



THE CHILDREN'S IBD CENTER AT MOUNT SINAI

SPRING 2006

My Son Stephen— Getting his life back

By Linda McNeer

Stephen was diagnosed with UC when he was 7. At 8, he had a real crises episode with copious bleeding. Fortunately, the episode was controlled with steroids and no other real problems presented for almost two years. However, by the age of 10 he was using more steroids to control the frequent, recurrent bleeding. This was not as effective. In mid-June shortly after his 11th birthday Steve began to bleed and have diarrhea and vomiting. He was hospitalized for almost four weeks at a New Jersey hospital. We realized that the staff was doing everything but nothing seemed to work. They advised us to consider surgery—a sub-total colectomy with a J-pouch reconstruction when Steve had recovered a bit. We were reluctant but desperate. Several friends and trusted MDs suggested Mt Sinai.

Stephen was collected by a Mt. Sinai ambulance on a Monday in mid July. I rode in the front seat and was able to communicate with my child all the way. We were both pretty scared. His hemoglobin was 6. He was rushed into testing and given a special direct IV line for whole blood transfusion. He was losing more than four units per day. We were just out of time. His colectomy was performed on Wednesday. I later learned that the

New Features in this Season's Newsletter...

In this edition of the Children's IBD Center newsletter, we have introduced some new features. Linda McNeer, mother of a teenager with ulcerative colitis, tells the story of her families experience of inflammatory bowel disease. We plan to make personal stories a regular feature of the newsletter and hope to include stories and art work from children and teenagers in addition to stories from parents and grandparents. On the back of the newsletter is our new section featuring frequently asked questions. We invite you to submit general questions of interest to you by e-mailing or calling our office; while we cannot answer individual patient questions in this forum, we will try to include as many as possible in future editions of the newsletter. The questions will be answered by members of our multidisciplinary team, including physicians, nurse practitioners, dieticians and social workers. In addition, the front page article details lecture activity at the Center.

Issues of Importance— Quality of Life in Children & Adolescents with IBD and Surgery & IBD

By Bambi Fisher, LCSW

On Thursday, December 1, 2005 the Children's IBD Center at Mount Sinai invited Ilene West, a doctoral candidate with IBD herself, to present her current research initiative on this important subject. Ilene spoke of her own history of being diagnosed with Ulcerative Colitis at the age of 22. She detailed her rocky and sometimes humorous course of medicines and treatments until she decided, after one hard time too many, to have surgery at the age of 26. Today, as a healthy doctoral student at Yeshiva University, Ilene feels that quality of life in IBD is a subject that needs more investigating and a stronger knowledge base. With this in mind, she is seeking to better understand the impact on quality of life when a young person is diagnosed with IBD. The parents in the audience, upon hearing this presentation, had their heads nodding in agreement when Ilene touched on points they clearly understood about living and learning to cope with IBD. Many parents asked probing questions in order to better understand the issue and to learn how to best help their own children maintain a normal and fulfilling life

following this diagnosis. Mount Sinai's Children's IBD Center's expectation that our children and adolescents with IBD have as high a quality of life as possible was emphasized and all the parents and staff in attendance were in agreement that this topic needs continual discussion and attention. Thanks to Ilene for speaking of her IBD experience and her related research and thanks to all who attended.



Ilene West, M.A.

Dr. Michael Harris gave our February lecture on the topic of Surgery and IBD. Dr. Harris emphasized how, though medicine is the first choice of an approach with IBD, surgery can be a necessary alternative for certain patients. In a relaxed, clear and thorough style, and with the use of slides and stories, Dr Harris took participants through the broad range of options and the newer techniques now

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"regular" days for surgery are Mondays and Thursdays. His procedure went well and he was given a stoma and colostomy bag about waist height on the right side. After a slow initial 24 hours he was given a day on clear liquids, then creamy liquids for two days, then on the 5th or 6th day after surgery he was offered any solid food-within reason. He chose pepperoni pizza! After six weeks of keeping nothing down, after going right up to the edge between life and death--that piece of pizza was just like a miracle. We all watched him go for it. Two days later he came home.

We recovered during August and started school in September. The surgeon had said Steve could have his reconstruction as soon as his hemoglobin was 13 or 14. We ate like a training table eats. By early November his hemoglobin was 12.8 and the surgeon said "OK,OK you can have the second operation."

We came to back to Mt. Sinai in mid November. Steve had the more complicated J-pouch and pull through. His recovery was longer--about ten days in the hospital and a longer period at home. We had the best Thanksgiving in years! Steve was home tutored through our school district and put on "pass/fail" for that grading period. It was a great way to handle some of the academic stress.

Steve's long term recovery has been terrific. He wrestled in high school, took up scuba diving with his dad. And still enjoys hiking and camping. I won't say his transition from adolescence to adulthood was easy but I'm eternally grateful that I got to watch him grow up. I credit the surgical team at Mt. Sinai for giving my son a lifetime reprieve from a very nasty disease and a healthy outcome from a serious surgical procedure. You have my lasting gratitude.

By the way, our whole family is going scuba-diving for a week in March--about half way down the FL Keys.....Life is great.

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available to patients. Children are different than adults with regard to surgery, said Dr Harris. He spoke warmly of how children surprise him under difficult circumstances; bouncing back and healing far faster than one would imagine. One other difference in dealing with children and IBD and surgery is working with the parents. Dr Harris finds parents extremely knowledgeable these days, often knowing more than the pediatricians or internists. Detailed discussion of all surgical options, complications and outcomes is required with families considering surgery in a child with IBD, because, according to Dr Harris, it is important to minimize the surprises and the unknown. Mount Sinai Pediatric IBD Center doctors and staff work closely with Dr Harris. According to Dr. Harris, there is no magic bullet, but surgery, when needed, can be a blessing for the right patient.



Dr. Michael Harris, M.D.

Questions? Concerns? Ask the Team...

Q: Why should you take your medication when you feel fine?

A: Many patients, parents and health care professionals do not like the idea of excessive use of medications. Inflammatory bowel disease can be a chronic illness with relapsing symptoms that can be very debilitating. Particularly in children, the persistence of symptoms often signifies that the disease is active and will prevent adequate growth. There are several circumstances where the use of long term medications might be beneficial.

In Crohn's disease, symptoms may be quiet but there may be a lack of growth. Many children benefit from maintaining some form of therapy until growth is completed, as long as the medication does not produce any toxicity. In addition, in patients who have had a surgical resection, there is a distinct chance of disease recurrence, within as little as two years after the surgery. Studies have demonstrated that maintaining a patient on a medication post-operatively will significantly decrease the chance of recurrence. Another area of preventive medication use involves patients newly diagnosed with ulcerative colitis. It is generally accepted that patients diagnosed within the prior 12 – 24 months, have a great chance of relapsing or worsening. Studies have demonstrated that by taking a maintenance medication, the chance of spreading or worsening of the disease is much less likely. **Keith J. Benkov, M.D.**

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

Join us at our next Children's IBD

Center Lecture:

Sending Your Child to Camp, 4/6/06, 6-7pm

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.