



Spring 2008

THE CHILDREN'S IBD CENTER AT MOUNT SINAI NEWSLETTER



In this Issue:

The IBD Center Staff—
Learn about Bambi Fisher,
our Social Worker; Kathy
Hoffstadter Thal, our
Research Coordinator; and
Renee Krutoff, our
Development Consultant
**Research at the IBD
Center—** Learn about an
exciting new research
project

**What's in a name? - A short
history of Crohn's disease**

Please join us for our next
lecture—Growth and
Inflammatory Bowel Disease
By Keith Breglio, MD
On 5/6/08, At The Zone
1184 Fifth Avenue, 1st Floor.

Psychological Well- being in Children with Inflammatory Bowel Disease

By Laura Regina, Ph.D. &
Carrie Masia Warner, Ph.D.

IBD is common in teenagers,
affecting about 200,000
youngsters in the US under the
age of 21. This medical condition
can disrupt school attendance,
socialization, and participation in
extracurricular activities. IBD
symptoms, such as stomach pain,
nausea, vomiting, and weight loss,
are unpredictable and can be

particularly distressing and
embarrassing for teens at a time
when they are overly concerned
with others' opinions, peer
acceptance, and becoming more
independent. Given that
adolescence is already a
challenging time, having IBD may
place teenagers at even greater risk
for developing anxiety and
depression. Often anxiety and
depression go undetected, resulting
in prolonged suffering, and for
youth with IBD, possible disruption
in disease management.

Anxiety Related to IBD

A number of teens with IBD worry
about having symptoms when they
leave home. For example, they may
worry that they will require repeated
or prolonged bathroom use or
experience recurrent and intense
pain. Fear of these symptoms may
result in difficulty going to public
places (e.g., movies, restaurants).
Therefore, it is important to better
understand the experience of
anxiety and depression in
teenagers with IBD.

Besides worries related to
their medical condition, teens can
experience a variety of anxiety
symptoms. Common forms of
anxiety include:

Separation Anxiety: Fears about
being away from close family
members or staying home alone.
Some common signs include
refusal to sleep alone, difficulty
attending school, and worry about
parents' safety.

Social Anxiety: Extreme shyness
or intense worry in social situations.
These children and adolescents are
often very self-conscious, and have
difficulty interacting with unfamiliar
peers. Discomfort may also be
related to public speaking,

performances, or playing sports.

Generalized Anxiety: These children
and teenagers are worriers! They
worry about school grades, family
finances, and the future. They hold
themselves to high standards and
appear to be "perfectionists."

Depression: Teenagers may
experience sadness, fatigue, and
feelings of worthlessness. They may
be irritable and moody, and lose
interest in activities that were once
pleasurable, such as playing sports,
or reading. Even when not severe,
depression can worsen and lead to
declining school performance and
impaired family and peer
relationships.

OPPORTUNITY TO PARTICIPATE IN RESEARCH

Dr. Laura Reigada, a clinical
psychologist at the NYU Child Study
Center has teamed up with Dr. Keith
Benkov, chief of the division of
Pediatric Gastroenterology at Mount
Sinai School of Medicine, and his
research team to learn more about
anxiety and depression, quality of life,
disease management, healthcare
usage, and the emotional impact of
having this disease for teens with
IBD.

If your child is 12 to 17 years
old and has a diagnosis of either
Crohn's Disease or Ulcerative Colitis
you can participate in this study.
Families are asked to fill out a
questionnaire packet which takes
about 15 minutes to complete.

To thank families for their
time a \$10 card will be given for filling
out the forms. If you are interested in
participating or learning more about
this project please contact Dr. Laura
Reigada, at NYU Child Study Center,
at 212-263-2474 or via email at
Laura.Reigada@med.nyu.edu.

Meet the Children's IBD Center Staff

The Psychosocial Corner with Bambi Fisher, Social Worker



Bambi Fisher, L.C.S.W.

Hello... I am a Licensed Clinical Social Worker and I coordinate the psychosocial programs for the Children's IBD Center at Mount Sinai Kravis Children's Center. I am fortunate to already know many of our newsletter readers. Yet, there are many of you I have not yet met, and who may be wondering "What is an L.C.S.W. and why would I need to use one?"

A licensed social worker is a master level social worker that must have many hours of supervised clinical psychotherapy work to be eligible for the LCSW license. The majority of my work has been with children, teens and families with chronic illness. I work with the multidisciplinary team at the Children's IBD Center to identify the needs of individual patients and families and to help find appropriate solutions and plans. For some families, this can mean offering counseling and guidance through the various phases of a child's diagnosis of IBD, or perhaps helping families advocate for their needs and finding the best services/resources; For

others, it is navigating the often confusing medical/hospital system. I connect families with similar concerns related to IBD and I recognize that, although the child is the focus of medical attention, frequently, it is the family as a whole that benefits from support and assistance. Helping families anticipate and understand some of the psychosocial concerns with IBD helps to normalize the issues and ultimately, improves coping. Together with the Children's IBD team, we offer a variety of lectures, meetings, Kids/CHAT groups, etc. with the goal of providing excellent educational and preventive care. We are always open to any new thoughts and suggestions. You can feel free to contact me at 212-241-9113 or at my email, bambi.fisher@mssm.edu.

The work of a Research Coordinator by Kathy Hoffstadter-Thal



Kathy Hoffstadter-Thal, P.N.P.

As the Research Nurse Coordinator my primary responsibility is to prepare research projects for the Children's IBD Center. I function as a liaison between the IBD Center staff and the Mount Sinai Institutional Review Board (IRB). The IRB is the department in the

the hospital which oversees *all* research being done in the hospital. The Research Coordinator is usually a Masters prepared nurse or other masters prepared professional. My previous experience as both a Pediatric Nurse and a Pediatric Nutrition Support Nurse working with many children with Inflammatory Bowel Disease at Mount Sinai Hospital has proved to be invaluable in my present position.

At the Children's IBD Center, I meet with our staff of physicians and nurses on a biweekly basis. At these meetings we discuss all of our research projects including those that are presently going on, those we would like to conduct and those that have already been sent to the IRB and are awaiting approval. Once we agree on a study that we would like to conduct or join, I write up the study and submit it to the IRB. There are different kinds of submissions depending on what you will be doing and how you will be conducting the study. In general, studies called retrospective chart reviews, which simply go back over existing charts/records to answer a question or observational studies, such as seeing what happens to patients who receive one medication as opposed to another, are the simplest and fastest to get approval for. Studies that involve a medication or treatment called treatment or interventional studies go through the most rigorous process.

The IRB is mainly interested in knowing that the study is being conducted in an ethical way and with the patients consent and authorization if needed. Once approved, the research can be conducted for one year and then needs to be resubmitted and reapproved by the IRB.

At the Children's IBD Center, I also maintain our database of more than 1200 children. In this database we keep patient information as an electronic chart. After we are approved for research by the IRB, we can "query" or ask a question and have the database sort through the information to find the answer.

Conducting research helps us to better understand how to treat inflammatory bowel disease and to work towards a cure.

Introducing Renee Krutoff—Development Consultant



Renée Krutoff

Renée Krutoff brings to her position as Development Consultant many years of experience as an executive with educational and health related non-profit organizations. With a background in organizational development, she has a commitment to high standards of excellence, with a proven ability to think strategically, to develop and implement programs and projects, and to motivate others.

Renée's diverse professional background lead to her position as the Executive Director of the Fairfield/Westchester Chapter of the Crohn's & Colitis Foundation of America (CCFA). Her accomplishments, during her seven years with CCFA, are too numerous to list. However, the Children's IBD Center at Mount Sinai was thrilled to recruit her for the excellent educational and family-friendly programs she initiated.

Prior to her tenure with CCFA, Renee was director of the North Atlantic Region of Jewish Women International (formerly B'nai B'rith Women) for seventeen years, and spent eight years with educational institutions, such as Empire State College. She was also Managing Partner in the development and public relations consulting firm of Hyatt-Krutoff Associates in New York City.

Renée earned her degree in Business Management and Economics from State University of New York. A professional driven by personal pride and a commitment to high standards of excellence, we are most fortunate to have her as an addition to the staff of the Children's IBD Center.

What's in a name? A short history of Crohn's Disease.

By Clare Ceballos, P.N.P.

Crohn's disease is named after a Mount Sinai Hospital physician, Burrill B. Crohn, who along with his colleagues Gordon D. Oppenheimer and Leon Ginzberg, first described a series of patients with "regional ileitis" in 1932. However, their work was predated by several earlier observations and case series.

In 1612 Gullielmus Fabricius Hildenus recorded his findings of a boy who had suffered with subhepatic pain. He noted that the boy's cecum was contracted, ulcerated and fibrous. Similar reports continued to be made in the next century, including descriptions by Giovanni Battista Morgagni in 1769 detailing an illness with intestinal inflammation and abdominal mass. In 1806 Coombe & Sanders reported what is widely regarded as the first case of Crohn's disease to the Royal College of Physicians in London. In 1823, John Abercrombie, a physician who worked from 1804 as a general practitioner in Edinburgh, Scotland, documented 144 cases highlighting differences between ileal and colonic disease. He was most likely recording Crohn's disease and ulcerative colitis.

One of the earliest descriptions of what we would call Crohn's disease was made by a Scottish surgeon, Thomas Kennedy Dalziel, in 1913. Dalziel was trained in surgery and pathology and in 1891 he joined the staff of the Royal Hospital for Sick Children in Scotland. His observations, of thirteen patients, were published in

the British Medical Journal in 1913, on the eve of World War I. He noted that these patients had disease involving the jejunum, mid ileum and transverse and sigmoid colon. Due to the political instability in Europe at the time, his paper did not receive the attention it deserved.

Further progress was made in describing this disease by two physicians from Mount Sinai Hospital, Eli Moschcowitz and Abraham Wilensky. In 1923 they reported a series of four patients, who developed an abdominal mass and obstruction after an episode of "acute appendicitis". Also at Mount Sinai Hospital Leon Ginzberg and Gordon Oppenheimer cared for another twelve patients also with distal ileal disease. These physicians were joined by Burrill Crohn, who in 1930 was caring for a teenage brother and sister with fever and right sided lower abdominal mass. Since all these physicians were working at the same hospital they were encouraged by the hospital pathologist, Paul Klemperer and the surgeon who had operated on all the patients, A A Berg, to coauthor work describing their experience with these patients.

In May of 1932 two presentations were given regarding this entity of "non-tuberculosis granulomatous enteritis". On May 3rd 1932, Leon Ginzburg read a paper in Atlantic City, written by himself and Gordon D. Oppenheimer, describing fourteen patients with "localized hypertrophic ulcerative stenosis of the terminal ileum". On May 13th 1932, Burrill Crohn presented a paper in New Orleans, on behalf of himself and Leon Ginzberg detailing fifteen patients with "regional ileitis". These findings were published in 1932 in the Journal of the American Medical Association and the entity of regional ileitis or Crohn's disease, was on the map.

The work of Crohn was predated by many previous observations and case series. If Dr. Berg had opted to be included in the 1932 paper, with its alphabetical listing of authors, Crohn's may have been Berg's disease; and if Dalziel had presented his paper at a time when Europe was not in the throes of starting World War I, he may have credited with Crohn's disease too.

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.

Internships: Is your High School or College age student looking for an internship? Internships are available at The Children's IBD Center. Minimum 6-8 hours a week. Contact 212-241-5415 or childrenibd@mssm.edu for more information.

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 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.



The printing of this newsletter was made possible by an unrestricted educational grant from Procter & Gamble Pharmaceuticals.



The Children's IBD Center at Mount Sinai

The Department of Pediatric
Gastroenterology

One Gustave L. Levy Place
Box 1656
New York, NY 10029

Tel: (212) 241 5415
Fax: (212) 832 7974

childrenibd@mssm.edu

Resources for Families:

www.IBDKids.org
www.CCFA.org
www.medlineplus.gov

Some suggestions from patients:

www.Crohnszone.com
www.dragonpack.com
www.healingwell.com

Please join for our next lecture:

5/6/08 at The Zone, 1184 5th Ave
Growth and Inflammatory Bowel
Disease

Please join us for IBDChat, an interactive group for kids with IBD + their siblings:

5/6/08 at The Zone, 1184 5th Ave

To register or for more information, call
212-241-5415 or email
childrenibd@mssm.edu