



# THE CHILDREN'S IBD CENTER AT MOUNT SINAI

SUMMER 2007

## A Sibling's Voice

By Jordan

### Just for a bit

Forgotten  
 Temporarily  
 Alone  
 For a bit  
 Crying  
 Signing  
 Unimportant  
 Minor detail  
 Just for a bit  
 Tides turn  
 Sunrises and sunsets  
 Darkness  
 Light  
 Hang to  
 Whatever you can  
 Just for a bit  
 Be strong  
 Just for a bit  
 Be strong  
 Just for a bit  
 I am a drifting  
 Cloud  
 And a sitting  
 Boulder  
  
 Just for a bit

## Summer at Last!

In this newsletter we have focused on two important topics—Research and Siblings. The Children's IBD Center at Mount Sinai not only provides clinical care, but is also involved in several research initiatives to investigate causes and eventual cures for Crohn's and colitis and ways to improve the lives of children living with these diseases. Having a child with a chronic illness impacts all family members and Jordan's poem reminds us of the impact on siblings. Finally a few reminders—The Children's IBD Center is once again a designated charity for the ING New York City Marathon on November 4th so plan to come out and cheer on Team IBDKids & e-mail us at [childrenIBD@mssm.edu](mailto:childrenIBD@mssm.edu) if you'd like to help.



## Research in Action



Keith Breglio, M.D., Pediatric GI Fellow, at work in the lab.

**M**y name is Keith Breglio. I just finished my second year of training as a Pediatric Gastroenterology Fellow here at Mount Sinai. Over the past year, I have spent the majority of my time in the laboratory performing research in inflammatory bowel disease. Under the direction of one of our adult gastroenterology colleagues, Dr. Maria Abreu, I have been looking at some of the possible causes of intestinal inflammation seen in inflammatory bowel disease. We are looking at the immune system, specifically the different cellular pathways in the immune system and their role in causing or preventing inflammation.

The exact cause of inflammatory bowel disease is still unknown. Basic science research allows us to look at just that, the basic science behind the development of inflammatory bowel disease. As continued research efforts bring us closer to understanding the cause, we can then seek specific treatments for Crohn's disease and ulcerative colitis that will lead to a definitive cure.

## Let's Talk about Siblings By Bambi Fisher, LCSW

**W**e see it all the time with our families at the Children's IBD Center. The struggle of how to balance the needs of the healthy siblings when a child is diagnosed with IBD or when a flare up pulls parental attention in the direction of the sick child. The family environment and routines are often altered when IBD is diagnosed or a flare up occurs. There is evidence that the psychosocial functioning and life experience of the well sibling

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# Quality of Life in Children with IBD

By Ilene West

**I**n June 2005, I began recruiting for my doctoral research project entitled, "Pediatric Inflammatory Bowel Disease and Psychosocial Functioning: A Focus on Social Competency and Quality of Life." Through the help, support, and cooperation of the families at the Mt. Sinai Children's IBD Center, some new light has been shed on important factors associated with assessing quality of living in pediatric IBD. A special thank you also needs to be delivered to the entire Children's IBD Center, for without support of this team, my project could not have come to pass.

The purpose of the above research study was to assess quality of life issues and related functioning in a subset of children and adolescents with Inflammatory Bowel Disease. Specific aims included exploring the relationship between duration of illness, age at onset, and quality of life in children with IBD. It was believed that the more active the disease, the lower the ratings of quality of life would be. Additionally, it was expected that quality of living would be negatively impacted by the amount and type of medications taken at time of recruitment. Parental perspectives of children's psychosocial well-being were expected to relate positively with children's subjective ratings on various study variables, such as self-esteem, social competency, depressive vulnerability, and quality of living.

Fifteen patients with IBD, followed at the Children's IBD Center, completed a survey of questionnaires concerning quality of life and psychosocial functioning while living with Crohn's disease or ulcerative colitis. The children's parents also completed a measure of social, emotional, and behavioral well-being. The questionnaires took 30 minutes

on average to complete, and were usually filled out at regularly scheduled office visits. Participants' treating physician also completed an objective measure of disease activity and severity.

The results from this study indicate that age at diagnosis is significantly related to several variables including self-esteem, depressive symptoms, and parental ratings of their children's behaviors. Regardless of disease activity and severity, other combinations of factors, including age at onset, may account for quality of life ratings and related psychosocial well-being. Interestingly, the older participants were not found to have more severe and active disease than younger participants, yet they had lower ratings of quality of life. These results further suggest that age at diagnosis, rather than length of time living with the disease, is a potential risk factor of psychosocial wellness and quality of living. While the aim of the study was to explore connections between quality of life in children with IBD, external variables, including social support within the treatment facility, may also play an influential role in psychosocial functioning and well-being.

All of the current studies on pediatric quality of living issues to date have been conducted with cross-sectional samples and do not allow for investigation of long-term psychosocial adjustment and well-being. In general, children with IBD appear to have difficulty adjusting to the illness, but specific consequences related to psychosocial and emotional well-being and risk

factors for adjustment remain unclear. Future research should focus on a long-term exploration of children with IBD, from onset of disease, spanning natural developmental transitions. The inconsistencies in some of the studies on adjustment may be addressed in more prospective studies that may uncover different groups of children who at first may experience much distress over the illness but learn to adjust and another group who have continued difficulty adjusting over time.

## Siblings Bambi Fisher, LCSW

*(Continued from page 1),*

well sibling of a child with IBD may be affected. The results of studies, often based on illnesses other than IBD, are mixed as many of our families can attest to. Siblings may experience higher levels of anxiety, isolation and even guilt (The "why not me?" or "Am I next?") On the positive side, however, siblings frequently develop greater maturity and sensitivity beyond their years. Often by necessity, they become emotionally patient, tolerant and flexible. Most important, the beauty of the sibling relationship becomes apparent when it is clear no one will do a better job treating the child with IBD as a "normal" sibling — the fighting, teasing and joking that only siblings can share continues. We invite your thoughts on this subject as well as those of any siblings. Please email me at [bambi.fisher@mssm.edu](mailto:bambi.fisher@mssm.edu).

### 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](mailto:ChildrenIBD@mssm.edu)

**PHONE:** 212-241-5415

**WEB SITE:** [www.IBDKids.com](http://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](http://www.IBDKids.com)

[www.CCFA.org](http://www.CCFA.org)

[www.medlineplus.gov](http://www.medlineplus.gov)

### Some suggestions from patients:

[www.Crohnszone.com](http://www.Crohnszone.com)

[www.dragonpack.com](http://www.dragonpack.com)

[www.healingwell.com](http://www.healingwell.com)

### Please join for our next lecture:

10/2/07 at The Zone, 1184 5th Ave

**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.**