



THE CHILDREN'S IBD CENTER AT MOUNT SINAI

FALL 2005

Research Projects at The Children's IBD Center

By Kathy Thal, MSN, RN, CPNP

I am the Research Coordinator for the Children's IBD Center. Below are the research projects that the Center is currently involved in.

ACORDIS is a drug study in affiliation with Massachusetts General Hospital. There are 30 sites involved in this study. The goals of the study are to identify an "optimal dose" for the drug azathioprine (also known as Imuran®) that is both safe and effective in the treatment of Crohn's Disease and to look at certain blood tests and their relationship to how patients respond to azathioprine.

Database study. We have over 1000 patients in our Children's IBD Center database which helps us track many aspects of their disease including response and tolerance to medications. This study looks at the response, safety and potential side effects of medication. Many medications are studied in adults but not children.

Pediatric IBD Network for Research and Improvement seeks to attain a network of 600 pediatric gastroenterologists (200 to start) looking at the variation of care in children with Crohn's disease who are on 6-mercaptopurine/azathioprine and infliximab (Remicade®). Specific interests are safety, quality improve

Fall Focus on Education & Research

In this newsletter we have focused on Education. Kathy Thal, our research coordinator at The Children's IBD Center, describes the research projects the Center is involved with. Bambi Fisher, our social worker, explains how educational laws can assist children with chronic illnesses, such as IBD, to be successful in school.

Come See & Enjoy our New Artwork



It's Good to Know It's There...Section 504: Federal Educa- tion Laws Affecting Children with IBD

By Bambi Fisher, LCSW

Students with chronic health problems, such as IBD, can function to their maximum potential if their needs at school are being met. Schools need to respond to the needs of children with IBD, in partnership with parents and health care providers, using the most comprehensive and coordinated approach possible. In cases where accommodating your child's health needs at school is better dealt with

in a formal way, the Section 504 of the Rehabilitation Act of 1973 may be important.

Section 504 is a civil rights law that prohibits discrimination on the basis of disability. It applies to all public schools and any private school receiving federal financial assistance. The goal of Section 504 is to insure that all schools provide reasonable accommodations in order to allow students with disabilities to receive an education that is comparable to that provided to students without disabilities.

Children with IBD are covered under this law if they can demonstrate that their health impairment substantially limits one or more of their major life activities. This needs to be documented. Major life activities under 504 include, but are not limited to, learning, walking, seeing, hearing, speaking, breathing, reading, writing, caring

Researcher with IBD Looks at the Emotional Impact of the Disease on Children

Kathy Thal, MSN, RN, CPNP

This study is being conducted by Ilene West, MA, a Mt. Sinai research volunteer/co-investigator and doctoral student at Ferkauf Graduate School of Psychology, Yeshiva University. Ilene was diagnosed with ulcerative colitis at the age of 22 and underwent surgery last year. She knows firsthand what it feels like physically and emotionally to suffer from IBD. Through her professional background and training as well as her own personal experience she seeks to examine the "Quality of Life" in children and adolescents with IBD.

Children and Adolescents often require ongoing medical treatment in order to control the symptoms of their disease such as diarrhea, rectal bleeding, abdominal pain and weight loss. The chronic and prolonged symptoms of IBD may create psychological stressors that are unique to this population, as compared with adults with the disease.

To date, there are limited research studies focusing on the developmental concerns and social acceptance of children with IBD. The physical symptoms associated with IBD may impair children's physical, social, and emotional functioning. Concerns regarding poor body image and appearance may hinder appropriate social adjustment and competency. The embarrassing nature of the physical symptoms associated with the disease along with the unpredictable and uncontrollable nature of their bowel's places children and adolescents with IBD at risk for social isolation. This study will compare the adjustment of children with IBD to healthy children and children with other chronic illnesses.

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for oneself and performing manual tasks. These are often interpreted broadly. It is important to note that Section 504 is not special education, which includes an individualized education plan (IEP) and which is designed to meet a child's unique educational needs. Section 504 seeks to eliminate obstacles preventing otherwise qualified students from participating in educational programs. It is common to get confused between the protection and needs of children with health problems and special educational needs and children with IBD related needs that educationally may not need special educational services.

Typical accommodations regarding children with IBD can include permitting extra absences for medical appointments and sick days when necessary and/or making academic adjustments for classroom time missed for medical appointments, taking extra trips to the bathroom whenever needed with accessibility to the most appropriate bathroom available, and eating lunch with appropriate time to finish and eating whenever necessary, if medically indicated. Providing equal opportunity to participate in nonacademic and extracurricular activities must also be afforded to children with disabling health problems.

Each child with IBD will have his or her own needs. If utilized, a Section 504 plan is individually developed. The process is to first determine eligibility. Then a plan is prepared and the necessary school personnel are involved and educated. Negotiations and resolu-

tion of problems often occur. Should there be an inability to agree on terms in your child's 504, there is a grievance procedure.

In our experience at Mount Sinai, most schools want what is best for your child and work hand in hand with parents and health care providers to meet their needs in the school system. This may or may not include using a 504 plan. The goal is to insure that a safe and supportive educational environment exists for your child with IBD and that he or she has the same opportunities, as do all other students.



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ment and research, growth before and during treatment, side effects and the value of certain blood tests as predictors of a successful outcome.

Pediatric IBD and Psychosocial Functioning Ilene West, PhD candidate from Yeshiva University is conducting a "quality of life" study in children with IBD. Similar studies have been conducted with adults but not with children. The effect of disease severity, disease activity and the use of corticosteroids (i.e. prednisone) on mood, socialization, self esteem and quality of life are evaluated.

Anxiety Study in affiliation with NYU. This study seeks to determine the usefulness of a cognitive based treatment program (type of talk therapy) in helping children with anxiety who also suffer from stomachaches.

We want to hear from you:

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WEB SITE: www.IBDKids.com

For updated information about Center events, please send us your e-mail address to:

childrenIBD@mssm.edu
or call **212-241-5415**

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

Join us at our next Children's IBD Center Lecture:

IBD in the News
Thursday 10/27/05, 4:30-5:30pm

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.