



**Tony Otley develops and tests tools for improving and assessing quality of life in children and youth with inflammatory bowel disease.**

## Dr. Tony Otley Pediatric Gastroenterology

### New tools aim to improve outcomes and quality of life in children and youth with IBD

Pediatric gastroenterologist Dr. Tony Otley constantly strives to help young people with inflammatory bowel disease (IBD) live healthier, more satisfying lives with less pain. As he points out, IBD is very difficult for children and youth.

“Symptoms like severe abdominal pain, fatigue and diarrhea can limit young people’s ability to take part in activities that are an important part of growing up,” says Tony. “And then there are treatment side effects, like acne and weight gain, and even stunted growth and osteoporosis. These can be very hard for kids to cope with.”

Tony has developed a web-based self-care program for young people with IBD, called ‘The Mission is Remission,’ in collaboration with IWK clinical psychologist Dr. Patrick McGrath.

“The program teaches young people the importance of diet and sticking to their medications, as well as stress management and relaxation skills which can help keep symptoms under control,” says Tony. “Research has proven that stress can play a role in inflammation of the gut, and thus perhaps in IBD as well.”

Patients and families who took part in the Nova Scotia Health Research Foundation/SickKids Foundation-funded pilot study were very satisfied. Now Tony and Patrick are making the website more user-friendly with support from the IWK Auxiliary. They aim to launch ‘The Mission is Remission’ as a multi-centre clinical trial to measure its impact on disease status and quality of life.

Quality of life is a key outcome measure in IBD. Several years ago, Tony developed a quality-of-life assessment tool, the IMPACT Questionnaire, which is now used in pediatric IBD clinical trials all around the world.

“We need to know if new medications being tested have an adverse or positive impact on patients’ quality of life, in addition to the effect on the disease,” explains Tony. “The new drugs are very effective but they can have serious side effects.”

At the same time, Tony is collaborating with IWK scientist Dr. Andy Stadyk and IBD researchers across Canada on the GEM study: Genetic, Environmental and Microbial Causes of Crohn’s.

Funded by the Crohn’s & Colitis Foundation of Canada, this five-year, \$5.5 million study will recruit 5,000 siblings and/or offspring of people with Crohn’s disease and follow them for five years.

“Whenever a participant develops Crohn’s, we will take samples and compare them to samples from healthy people, to see what is different,” says Tony. “This will hopefully allow us to identify triggers and early markers of disease, which could lead to targeted therapies to block the disease early on.”

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