We are pleased to announce that our 3rd HNPCC education night will be moderated by Dr. Zena Cohen. Dr. Gallinger will present an update on HNPCC. Dr. Bob Gryfe, a colorectal cancer surgeon at Mount Sinai Hospital will discuss surgery and screening in HNPCC.

We are also invited Dr. Mary Jane Esplen, professor at Toronto General Hospital, and head of an HNPCC support group, to discuss the impact of HNPCC on a family. Our evening will include patient interviews of their question-and-answer period for our audience. If you have HNPCC, please look for a floor with details of this night.

We are also sharing some audience comments from our last education night:

“Getting updates that impact my family is important.”

“Very interested in your education nights.”

“Well worth waiting to attend. We came over 100 km to be here.”

“Excellent — Very good question and answer period.”

“Thank you for your stories and advice — live strong!”
Do patients who have a colectomy as young children have the same bowel function as patients who undergo a colectomy as adults? There is much less research about this, so we need to keep an eye on the number and size of the polyps. There is a small group of patients with FAP who develop many polyps at an early age and have more severe form of the disease. These patients require extra-intervention usually including surgery (colectomy) at a much younger age than most people with FAP.

People with classic FAP often have some polyps by age 10 to 12. It is important to have a first sigmoidoscopy between age 10 and 12 in order to detect polyps and begin intervention, if you notice them. The recommendations for Canada and the United States are to have annual colonoscopies after this first sigmoidoscopy. This allows children and adolescents to learn to take care of their bodies from an early age, which can help in the future, when they grow into adults. In a questionnaire sent to our adult Registry patients and their families, we asked about the lack of knowledge among health professionals; changes in availability of these guidelines; and their sensitivity for their families. In a questionnaire sent to our adult Registry patients and their families, we asked about the lack of knowledge among health professionals; changes in availability of these guidelines; and their sensitivity for people needs. There are many quality of life measures for patients and their families. In a questionnaire sent to our adult Registry patients and their families, the following problem were highlighted: concern about the lack of knowledge among health professionals; changes in availability of these guidelines; and their sensitivity for people needs. It is important to address these issues as soon as possible. There is much less research about this, so we need to keep an eye on the number and size of the polyps. There is a small group of patients with FAP who develop many polyps at an early age and have more severe form of the disease. These patients require extra-intervention usually including surgery (colectomy) at a much younger age than most people with FAP.

STUDY AID

Many of the studies and articles in pediatric FAP focus on those with MAD Little has been written about families of children with FAP. In particular, no articles have focused on the very young children with FAP and how their care should be approached. A first sigmoidoscopy should be performed every year. Some children and teens with FAP do not have an annual colonoscopy. We are interested in finding out why some children do not have the annual tests. Are there things that health care workers can do to ensure that children have the annual colonoscopies? As part of this project, we will look at barriers to surveillance in kids and teens. We are interested in looking at the outcomes of children with FAP who had a colonoscopy at age 12 or younger. We want to find out how a patient’s bowel function is after surgery and later in transition and adult life. Do patients who have a colonoscopy at young children have the same results as adults who have a colonoscopy? What is their quality of life? The second issue we want to study is two-fold: how children cope with the operation; and how the whole family has coped with having a very young child who needs to have surgery. People with classic FAP often have some polyps by age 10 to 12. It is important to have a first sigmoidoscopy between age 10 and 12 in order to detect polyps and begin intervention, if you notice them. The recommendations for Canada and the United States are to have annual colonoscopies after this first sigmoidoscopy. This allows children and adolescents to learn to take care of their bodies from an early age, which can help in the future, when they grow into adults. In a questionnaire sent to our adult Registry patients and their families, we asked about the lack of knowledge among health professionals; changes in availability of these guidelines; and their sensitivity for people needs. There are many quality of life measures for patients and their families. In a questionnaire sent to our adult Registry patients and their families, the following problem were highlighted: concern about the lack of knowledge among health professionals; changes in availability of these guidelines; and their sensitivity for people needs. It is important to address these issues as soon as possible.
for annual consultations and then have to return at another.

families report frustration in having to travel large distances "first-hand" about their experiences with FAP. For instance, from children, teens, and/or young adults who could tell us what issues are relevant. Please let us know if you have

whole family has coped with having a very young child who

two-fold: how children cope with the operation; and how the

is currently being designed. It would be very helpful to hear specific suggestions or thoughts to include in this study that

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What to Expect with Early-Onset Kids…What to Expect with Early-Onset

For patients who have a colectomy as young children have the annual

at the outcome of children with FAP who had a colectomy at

How to prepare for your visit less disruptive to the family. Your input helps us to look

HNPCC (Lynch Syndrome) is not just a hereditary colorectal cancer condition. For many families, there are several other types of cancer that can be associated with HNPCC. These include endometrial, ovarian, small bowel, stomach, upper urinary tract, primary pericardial, primary brain, and a very rare skin cancer called sebaceous carcinoma. Although the chance of developing these non-colorectal cancers is less than the risk for colorectal cancer, screening may be an option for some families. The second most common HNPCC is endometrial (mucinous) cancer for women. There are early signs and symptoms associated with this type of cancer, mostly in bones or heart or vaginal bleeding. Watching for these symptoms and having them investigated promptly for a speedy

time for the colonoscopy. This can be costly, requiring additional time off school and away from friends. Patients and their families may have about the frequency and age of any additional screening for the non-colorectal cancers; however, the assessment of these screening techniques is limited.

This allows children and adolescents to keep an eye on the number and size of the polyps. There is a small group of patients with FAP who develop many polyps at an early age and have to have annual colonoscopies after this first sigmoidoscopy. This allows children and adolescents to keep an eye on the number and size of the polyps. There is a small group of patients with FAP who develop many polyps at an early age and have to have annual colonoscopies after this first sigmoidoscopy. This allows children and adolescents to keep an eye on the number and size of the polyps. There is a small group of patients with FAP who develop many polyps at an early age and have to have annual colonoscopies after this first sigmoidoscopy.

People with hereditary colorectal cancer conditions have different ways of getting screened in their lifetime. For instance, some patients are offered genetic counseling at the age of 12 or younger. We want to find out how a patient’s bowel function or after surgery (and later in men) is abnormal. When patients who have a colostomy at age 12 or younger need in being part of either study or have any suggestions, please contact the editorial office or on the Registry.

One of the most common features of hereditary cancer conditions is young age of cancer diagnosis. Traditionally, the age of colorectal cancer diagnosis in the general population is in the mid-40s. For the hereditary conditions, the age of diagnosis is less than age 40, and the development tends to be more aggressive for younger patients. How old are your patients? Do your patients with hereditary colorectal cancer have any additional screening for the non-colorectal cancers; however, the assessment of these screening techniques is limited.

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Kids…What to Expect with Early-Onset Familial Adenomatous Polyposis (FAP) (continued)

CLINICAL FOCUS

What is FAP?

FAP is an inherited colorectal cancer condition. People with classic FAP often have polyps by age 10 to 12. It is important to have a first sigmoidoscopy by age 10 and 12 in order to detect polyps. If abnormalities are found, colonoscopy should be performed every year. Some children with FAP require earlier intervention usually including surgery (colectomy) at a much younger age than most people with FAP.

Most of the studies and articles in pediatric FAP focus on teens with FAP. Little has been written about early childhood FAP with children FAP. In particular, no articles have focussed on the psychological effects of having FAP to young children. In this study, we aimed to gain an understanding of the psychological effects of having FAP seen in young children.

Familial Adenomatous Polyposis (FAP)

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Updating our education programs for colorectal cancer screening: the familial component.

Glossary:

**Hereditary Non-Polyposis Colorectal Cancer (HNPCC):** A hereditary condition which poses a high risk of developing colorectal cancer, as well as an increased risk for other gastrointestinal cancers.

**Jenner Polyposis Syndrome (JPS):** A condition characterized by the development of a specific type of polyp (heterotopic) in the gastrointestinal tract, usually within the last 20 years of life. It can develop sporadically or it can be inherited.

**Keratoacanthomas:** A benign, rapidly growing skin tumor, usually forming on an exposed area of skin, typically developing on one or more localized lesions, and can be treated by surgical excision.

**Massive Tumor Syndrome:** A variant of HNPCC, characterized by a combination of colorectal cancer and other non gastrointestinal cancers.

**Multiple Adenomatous Polyposis (MAP):** A recently identified hereditary condition characterized by multiple polyps and colorectal cancer. MAP is caused by genetic changes, called mutations, in the MYH gene.

**Peutz-Jeghers Syndrome (PJS):** A hereditary syndrome causing the development of dark freckles on the skin, characteristic polyps in the small intestine, small bowel, stomach, colon, and sometimes in the nose or bladder, and an increased risk of some cancers.

**Muir-Torre Syndrome:** A rare autosomal-dominant tumor syndrome that usually presents as a small, yellow bump.

**MYH-Associated Polyposis (MAP):** A recently identified hereditary condition characterized by multiple polyps and colorectal cancer. MAP is caused by genetic changes, called mutations, in the MYH gene.

**Peutz-Jeghers Syndrome (PJS):** A hereditary syndrome causing the development of dark freckles on the skin, characteristic polyps in the small intestine, small bowel, stomach, colon, and sometimes in the nose or bladder, and an increased risk of some cancers.

**Sebaceous Adenomas:** A benign tumor developing on the skin, usually occurring in a small, yellow lump.

**Sigmoidoscopy:** A procedure in which the sigmoid colon is examined by inserting a flexible tube (colonoscope) into the rectum.

**Stomach:** A hollow, muscular organ in which food is digested and absorbed into the bloodstream.

**Surgery:** A medical procedure performed by a surgeon, a doctor who specializes in performing operations.

**Surgical removal of all or part of the colon:** A surgery performed to remove a part of the colon.

**Sympathetic nervous system:** A division of the autonomic nervous system that regulates heart rate, blood pressure, and other functions.

**The surgical removal of all or part of the colon:** A surgery performed to remove a part of the colon.

**Thoracic duct:** A lymphatic vessel that carries lymph from the lower limbs and trunk to the left subclavian vein, a major vein that carries blood from the upper body to the heart.

**Ultrasound:** A non-invasive medical procedure that uses sound waves to create images of the inside of the body.

**Urinary tract:** The system of tubes and organs that carry urine from the kidneys to the bladder, where it is stored and then expelled from the body.

**Vesical diverticulum:** A pouch-like enlargement of the bladder that can develop in response to bladder irritation or injury.

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**UPDATE**
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**Very interested** — Very good education night.

**Well worth waiting to attend.**

**Thank you for your stories and advice — live strong!**

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**GLOSSARY**

**Colorectal:** the surgical removal of all or part of the colon.

**Esophagogastroduodenoscopy (EGD):** A procedure in which the esophagus, stomach, and duodenum (first portion of the small intestine) can be examined and can be viewed on a monitor, using a flexible tube (scope).

**Familial Adenomatous Polyposis (FAP):** An inherited disease in which multiple polyps (hundreds or thousands) develop in the colon and rectum, which can lead to colorectal cancer. FAP can be inherited or can be caused by a mutation in a single gene, often caused by a mutation in a single gene.

**Familial Gastrointestinal Cancer Registry:** A hereditary condition that is a rare, life-long condition like FAP at a young age can build an individual to think and focus on different situations and others talked about concerns of passing on the condition to their children.

**Turcot’s Syndrome:** A syndrome characterized by the development of cancer in the colon and rectum, which can be inherited or can be caused by a mutation in a single gene.

**Gastroenterologist:** A doctor specializing in diagnosing and treating problems with the digestive system.