Familial Adenomatous Polyposis (FAP): What You Should Know

Nebraska Colon Cancer Screening Program

Although FAP may affect only 1 in 10,000 people, it is considered a model for cancer prevention throughout the world. The key to treatment for FAP is education.

Familial means that it runs in families. Each child of an affected parent has a 50% risk of inheriting the disease gene.

Adenomatous is a type of mushroom-shaped growth or polyp, which may be precancerous.

Polyposis is a condition where 100 or more polyps can form in the large intestines.

The word "polyp" refers to a lump of cells which form a tissue mass. A polyp must be checked under the microscopy (biopsied) to determine whether it is harmless (benign) or precancerous (premalignant). In FAP, abnormal cells form over time and clump together into pre-cancer adenomas.

Adenomas may be as small as 1-2 mm when they form or as large as 4-5 cm when they change to cancer. Adenomas develop on the surface lining of the intestine, particular the large intestine.

What are the symptoms?

Polyposis of the colon most commonly causes no symptoms but it may cause:

- Blood/Mucus in the stool
- Occasional crampy abdominal pain and/or weight loss
- Diarrhea

How is FAP diagnosed?

Most commonly, FAP is diagnosed when a relative of a known FAP-affected individual is screened using flexible sigmoidoscopy or colonoscopy, in which the doctor looks at parts of the colon through a small tube inserted into the rectum.

Genetic diagnosis is increasingly available. This is usually done by a process known as linkage analysis, which requires blood or cells from inside the cheek collected by mouth washings from at least two other living affected family members. It detects approximately 95 percent of cases with 98 percent accuracy.

Eventually the diagnosis will probably be based on identifying the gene mutation in a blood sample, but most families have different mutations and identifying all the components of the entire gene is currently a very long process.

Treatment

Children of affected parents should be screened by flexible sigmoidoscopy or colonoscopy every year from the age of 10 until the age of 35 and every three years thereafter.

Once a diagnosis of FAP is made, upper gastrointestinal endoscopy should be done every two to three years to look for duodenal disease. Once FAP has been confirmed, colon removal (colectomy) should be planned, usually by the age of 14.

There are two main surgical options: 1) total removal of the colon and rectum, and 2) removal of the colon without the rectum.

Additional Resources

Mount Sinai Hospital	www.mtsinai.on.ca
National Digestive Diseases Information Clearinghouse – a service of the National Institute of Diabetes and Digestive and Kidney Diseases	http://digestive.niddk.nih.gov

For More Information:

Nebraska Colon Cancer Screening Program
301 Centennial Mall South, P.O. Box 94817
Lincoln, Nebraska 68509-4817
Phone: 1-800-532-2227 TDD: 1-800-833-7352 Fax: 402-471-0913
www.dhhs.ne.gov/crc or www.StayInTheGameNE.com
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