



Dear Family Member,

A member of your family has been identified as having a genetic mutation in the **APC gene**. Mutations in this gene are known to be associated with an increased risk for certain cancers. This means that other family members are at risk to carry this same gene mutation and hence at an increased risk for certain cancers. This letter has been written to summarize information regarding *APC* mutations.

A gene mutation in the *APC* gene causes **Familial adenomatous polyposis (FAP)**. FAP is an inherited disorder characterized by colon and rectum cancer. People with the classic type of FAP have hundreds to thousands of benign polyps in the colon (polyps may start to develop as early as their teenage years). Unless the colon is removed, these polyps will become malignant. The average age at which an individual develops colon cancer in classic FAP is 39 years. Some people have a variant of the disorder, called attenuated familial adenomatous polyposis, in which polyp growth is delayed. The average age of colorectal cancer onset for attenuated familial adenomatous polyposis is 55 years. In both classic familial adenomatous polyposis and its attenuated variant, benign and malignant tumors are sometimes found in other places in the body, including the duodenum, stomach, bones, skin, desmoid tumors, and other tissues. People who have colon polyps as well as growths outside the colon are sometimes described as having Gardner syndrome.

Understanding risk is an important tool in prevention and management of cancer. It is important to note that many individuals with *APC* mutations will never develop cancer over their lifetime. When one inherits an *APC* mutation, he/she is not inheriting cancer; rather they are inheriting a predisposition to cancer.

When an individual has one copy of the *APC* gene mutation, they have an increased risk for cancer as outlined above. Because everyone has two copies of the gene for *APC*, this means that a parent who carries an *APC* mutation has a 50% chance of passing the mutation onto each of their children. It also means that if a person carries such a mutation, their siblings have a 50% chance to carry the same mutation. Extended family members may also be at risk for having the same mutation. If a person does not carry the mutation, they cannot pass it onto their children. Although most individuals diagnosed with an *APC*-associated polyposis condition have an affected parent, around 20% of cases are a due to a *de novo* mutation, meaning resulting from new mutations in the *APC* gene and occur in people with no history of the disorder in their family.

**We strongly recommend that you and all persons in your family who are at risk for carrying the *APC* gene mutation consider scheduling an appointment for cancer genetic counseling to discuss the benefits and limitations of genetic testing.** To pursue cancer genetic testing, it is helpful if you have a copy of your family member's genetic testing report indicating that they have an *APC* mutation.

GeneScreen is available to discuss this information in more detail with you and coordinate appropriate testing. **Please visit the following website to submit your request for genetic counseling:** <https://hipaa.jotform.com/200926739003048>. You can also contact Genescreen directly at 908-766-2800 to schedule a remote consultation with a genetic counselor.



***Genetic Counseling Service***

75 Claremont Rd Suite 305

Bernardsville, NJ 07924

Sincerely,

**Stephanie Nunziato-Virga, MS, LGC**  
Senior Oncology Genetic Counselor  
Genescreen

**Jill Chisholm, APN**  
President  
Genescreen