Understanding Your Positive AIP Genetic Test Result
INFORMATION FOR PATIENTS WITH A PATHOGENIC MUTATION OR VARIANT, LIKELY PATHOGENIC

5 THINGS TO KNOW

1. **AIP mutation**
   Your testing shows that you have a pathogenic mutation or a variant that is likely pathogenic in the AIP gene.

2. **Familial isolated pituitary adenomas**
   People with AIP mutations have familial isolated pituitary adenomas (FIPA).

3. **Non-cancerous tumor risks**
   You have an increased chance to develop non-cancerous tumors in the pituitary gland.

4. **What you can do**
   There are risk management options to detect tumors early. It is important to discuss these options with your doctor, and decide on a plan that best manages your tumor risks.

5. **Family**
   Family members may also be at risk – they can be tested for the AIP mutation that was found in you.

**AIP MUTATIONS IN THE FAMILY**

There is a 50/50 random chance to pass on an AIP mutation to your sons and daughters. The image to the right shows that both men and women can carry and pass on these mutations.
# Understanding Your Positive AIP Genetic Test Result

**INFORMATION FOR PATIENTS WITH A PATHOGENIC MUTATION OR VARIANT, LIKELY PATHOGENIC**

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Your testing shows that you have a pathogenic mutation (a disease-causing change in the gene, like a spelling mistake) or a variant that is likely pathogenic in the AIP gene. Both of these results should be considered positive.

Everyone has two copies of the AIP gene, which we randomly inherit from each of our parents. Mutations in one copy of the AIP gene are associated with an increased chance to develop non-cancerous pituitary tumors.

People with AIP mutations have familial isolated pituitary adenomas (FIPA).

You have an increased chance to develop non-cancerous tumors in the pituitary gland (pituitary adenomas). The pituitary gland is located in the brain and produces hormones to regulate many body systems, such as the thyroid, bone, kidneys, skin and many more. Pituitary adenomas can impact the hormone levels produced by the gland, which may cause headaches, vision problems, infertility, excess growth of hands, feet, and face, and other medical concerns.

Options for screening and early detection may include annual physical examination and imaging (type and frequency may vary). Screening options should be regularly discussed with and managed by a doctor familiar with FIPA, such as an endocrinologist.

Risk management decisions are very personal, and the best option depends on many factors. Screening typically begins earlier than in the general population, and is often more frequently done. It is important to discuss these options with your doctor.

Your close relatives (like your parents, brothers, sisters, children) have a 50/50 random chance of inheriting the AIP mutation that you carry, and other family members (like your aunts, uncles, cousins) may also inherit it. Your relatives can be tested for this same mutation. Depending on the family history, those who DO NOT have it may not have an increased lifetime chance (above the general population) to develop non-cancerous pituitary tumors.

It is recommended that you share this information with family members so they can learn more and discuss this with their healthcare providers.

**REACH OUT**

- American Brain Tumor Association [abta.org](http://abta.org)
- American Cancer Society [cancer.org](http://cancer.org)
- Association for Multiple Endocrine Neoplasia Disorders (AMEND) [amend.org.uk](http://amend.org.uk)
- Genetic Information Nondiscrimination Act (GINA) [ginahelp.org](http://ginahelp.org)
- National Society of Genetic Counselors [nsgc.org](http://nsgc.org)
- Canadian Society of Genetic Counsellors [cagc-accg.ca](http://cagc-accg.ca)

Please discuss this information with your healthcare provider. The cancer genetics field is continuously evolving, so updates related to your AIP result, medical recommendations, and/or potential treatments may be available over time. This information is not meant to replace a discussion with a healthcare provider, and should not be considered or interpreted as medical advice.