*Genetic Counseling Service*
30 Lafayette Avenue, Ste 1 #1010
Morristown, NJ 07960

Dear Family Member,

A member of your family has been identified as having a genetic mutation in the SDHA 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 of carrying this same gene mutation and hence at an increased risk for certain cancers. This letter has been written to summarize information regarding SDHA mutations.

Individuals with a mutation in the SDHA gene have a condition called hereditary paraganglioma and pheochromocytoma (PGL/PCC) syndrome. Hereditary paraganglioma-pheochromocytoma is characterized by tumors originating in the neuroendocrine tissues that are part of the sympathetic and parasympathetic nervous systems. Paragangliomas and pheochromocytomas are often noncancerous (benign) however some can become cancerous (malignant) and spread to other parts of the body (metastasize). These tumors may secrete excess hormones (such as epinephrine, norepinephrine, and dopamine (our "fight or flight" hormones)). Symptoms may include high blood pressure, along with headaches, rapid heart rate, and heavy sweating, The primary treatment for a pheochromocytoma is surgery to remove the tumor**.** Additional cancer risks include GIST (gastrointestinal stromal tumors), thyroid cancer, brain tumors (neuroblastoma), and kidney cancer (renal cell carcinoma).

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

When an individual has one copy of the SDHA gene mutation they have an increased risk for cancers as outlined above. Because everyone has two copies of the gene for SDHA, this means that a parent who carries a SDHA 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.

We strongly recommend that you and all persons in your family who are at risk for carrying the SDHA 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 SDHA 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: Family Testing Request (jotform.com) You can also contact Genescreen directly at 908-766-2800 to schedule a remote consultation with a genetic counselor.

Sincerely,

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

**Jill Chisholm, APN**
President
Genescreen