



**Genetic Counseling Service**

75 Claremont Rd Suite 305

Bernardsville, NJ 07924

Dear Family Member,

A member of your family has been identified as having a genetic mutation in the **DICER1 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 DICER1 mutations.

**Individuals with a mutation in the DICER1 gene have an increased risk for various benign and malignant tumors.** Studies have demonstrated an increased risk for tumors including pleuropulmonary blastoma (cancer originating in the lung or pleural cavity), cystic nephroma (cystic renal tumors), ovarian sex cord stromal tumors (ovarian germ cell tumors), multinodular goiter and thyroid cancer, embryonal rhabdomyosarcomas (cancer that develops from skeletal muscle cells), ciliary body medulloepithelioma (type of brain tumor), nasal chondromesenchymal hamartomas (benign tumor of the sinonasal tract usually presenting in infants), and pituitary blastoma, as well as various other tumor types. At this time, lifetime risks for each tumor type have not been well described.

Understanding risk is an important tool in prevention and management of cancer. It is important to note that many individuals with DICER1 mutations will never develop cancer over their lifetime. When one inherits an DICER1 mutation, he/she is not inheriting cancer; rather they are inheriting a predisposition to cancer.

When an individual has one copy of the DICER1 gene mutation they have an increased risk for cancers as outlined above. Because everyone has two copies of the gene for DICER1, this means that a parent who carries an DICER1 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 DICER1 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 DICER1 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.

Sincerely,

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Senior Oncology Genetic Counselor  
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