Instructions: Please find below suggested wording for a letter to your family members. If possible, you might consider talking to your relatives about your Lynch Syndrome testing first and then sharing the letter with them to help them remember what you discussed. Please read through this letter, fill in missing information, and make any additional changes you feel are needed. If possible, include a copy of your genetic testing results or informational sheet on your particular genetic change (mutation) with the letter. These results will be important for your relatives when they speak with their healthcare providers. This letter only applies to blood relatives. Blood relatives include your parents, grandparents, children, siblings, aunts, uncles, nieces, nephews, and cousins not related to you by marriage. Don’t forget to remove these instructions prior to printing.
Dear [Family Member Name],

I’m writing to let you know that I have been diagnosed with an inherited condition called Lynch syndrome, or Hereditary Non-Polyposis Colorectal Cancer (HNPCC). Lynch syndrome runs in families and is due to errors in certain genes (known as mutations). People with Lynch syndrome are much more likely to get colorectal cancer as well as other types of cancer. It is important to note if you have Lynch syndrome, it does NOT mean that you will definitely get cancer.

Because I have Lynch syndrome, my immediate blood relatives (parents, siblings, and children) have a 50% chance (1 in 2) of having Lynch syndrome. My other blood relatives (aunts, uncles, nieces, nephews, and cousins) might also have Lynch Syndrome. You are my blood relative, and so you are more likely to have Lynch syndrome and could benefit from genetic counseling and possibly genetic testing for Lynch syndrome. Please note that genetic testing for Lynch syndrome is not recommended for children under 18 years old, but can be considered when they reach adulthood.

If you find out that you have Lynch syndrome, you can take steps to lower your chances of getting cancer and to find cancer earlier if you do get it. These steps include earlier, more frequent, and additional cancer screening or preventative surgery.

People with Lynch syndrome are more likely to get certain types of cancers, including colorectal cancer, endometrial (uterine) cancer, ovarian cancer, biliary tract cancer, skin tumors, and urinary tract cancer. The attached document shows the specific mutation (change in gene) I have and this gene change is the one my family members should be tested for.

The first step is to discuss this with your doctor who can provide you with more information about genetic testing for Lynch syndrome. Your doctor may refer you to a genetic counselor. You can find the Washington State Cancer Genetics Clinic nearest you at http://www.doh.wa.gov/geneticclinics.

For more information about Lynch syndrome, here are some helpful resources:

- www.cancer.net/cancer-types/lynch-syndrome
- www.cdc.gov/Features/LynchSyndrome/
- http://doh.wa.gov/Lynchsyndrome

I understand that it can be hard to hear that you and others in our family could have Lynch syndrome. However, knowing about this risk is the first step in protecting yourself from getting cancer, and I want to help make sure that you and others in our family know about this important information. Please let me know if you have any questions.

Sincerely,

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