Human Genome FAQs:

I hear that there is a new scientific finding about a gene to test for Waldenstrom's Macroglobulinemia (WM). Is this true?

Good news travels fast. There is new data that suggests that we may be able to find where WM occurs on the DNA. The information has been submitted to a scientific journal. We expect that the information should be published, and therefore made public, sometime in early 2012. Please check back often, as it will be posted as soon as possible at the Bing Center for Waldenstrom's Macroglobulinemia Website.

Can I be tested? Can my family be tested?

The short answer is, not yet. The development and approval for a commercially-available test is a long process. It is not available for routine testing. Currently this test is only being performed in the setting of a clinical trial. Click here for more information about clinical trials at the Bing Center for WM. For WM trials throughout the US, you can search at www.clinicaltrials.gov

If I have MGUS, can the test tell me if I will develop WM?

Again, the short answer is, not yet. The test isn't yet available for routine testing. Because of that reason, we cannot test patients with MGUS at this time. Hopefully, the test will become more widely available in the future.

If I'm not tested for the gene, how am I certain that I have WM?

The gold-standard for the diagnosis of WM remains a biopsy, typically of the bone marrow, but can also include lymph nodes. If you have been diagnosed with WM in this manner, there is no reason to be retested by DNA. Keep in mind that the genome data is still very new. This test is not yet being used to predict response to treatment, life expectancy, or as an early test to see if a family member will develop WM. The Bing Center is committed to furthering this research, but that type of information may take years to understand.

What does this mean for the future of WM treatments?

There is very good news in this area. The new findings may direct us towards targeted therapies which may lead to the development of more effective treatments. Currently, discussions are happening to look at some drugs already in development, as well as identifying new molecules to overcome the abnormal function of that area of DNA. The drug development process is complex. We expect that early clinical trials for new therapies could begin as early as spring 2012.

I think I may have been one of the patients in the study. Can I get my test results?

Individual reports are NOT available. The Bing Center and the entire WM community owe a debt of gratitude to people who have donated their samples to be studied. The human genome has been reported to our researchers as millions of base pairs in raw data. There is no interpretive report that accompanies each genome. Because of this, the data is not in a format that can be shared with, or easily understood by patients and even most physicians. It is being interpreted by research scientists at this time. This information is stored in a separate database, and is not included in your medical records.

How can I get more information?

Please understand that we are all very excited about this data. Unfortunately, we are a small center and do not have the resources to answer routine phone calls and emails about this test. More information will be shared with the medical community through published data in medical and scientific journals. For patients, please bookmark the following websites, and check back often for updates.

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