

Appendix D: Posting for website

Medical Questionnaire and Tissue Banking for Multiple Myeloma, Waldenstrom Macroglobulinemia and Related Disorders

What is this study?

The purpose of this study is to obtain peripheral blood, buccal and bone marrow samples, along with clinical, epidemiological and dietary data from patients with Multiple Myeloma (MM), Waldenstrom Macroglobulinemia (WM), Smoldering MM (sMM), and other lymphoplasmacytic lymphomas (LPL) including but not limited to monoclonal gammopathy of undetermined significance (MGUS) and IgG or IgA LPL. Additionally, we will be collecting peripheral blood and buccal samples from consenting family and non-family members of patients with these diseases. These samples, which can contain malignant cells as well as normal cells, will be used to investigate cell genetics, the cancer cell microenvironment, host immune responses, tissue microarrays for immunohistochemistry, characterization of the effects, and complications of therapy. It is known that tumor cells have altered gene and protein expression and affect immune function and many of the therapies we use result in further changes in the immune system. The presence of malignant cells can also affect other host cells in the microenvironment of the tumor cells. Understanding these processes will help us to better direct our efforts in designing more specific, more effective and less toxic therapies. Investigators affiliated with the study will use the information you provide, along with bone marrow and blood samples, to conduct research to help increase our understanding of the causes of MM, WM, MGUS, sMM, and other LPLs, and to better direct our efforts in designing more specific, more effective and less toxic therapies. This research study has been approved and will be monitored by the Institutional Review Board (IRB) of the Dana-Farber Cancer Institute, Boston, MA.

If I enroll in the study, what will I have to do?

If you have Multiple Myeloma, Waldenstrom Macroglobulinemia, MGUS, Smoldering MM, lymphoplasmacytic lymphoma or another related disorder and would like to participate in the study, we ask that you read and sign two of the attached consent forms and complete the questionnaires or contact us at the address below. If you enroll, you will be asked to consent to our obtaining your medical records and speaking with your physician. We may also interview you at your convenience over the telephone and ask if you have family and non-family members interested in participating on this study. We will ask for 1-2 tablespoons of bone marrow and 2-4 tablespoons of blood to be sent to the Dana-Farber Cancer Institute, to be used for research studies and stored in a sample repository for future use. Buccal samples may be collected once and involve a swabbing back and forth of the inside of the cheek. If you prefer not to donate bone marrow, buccal and blood samples, you can still participate in the study by signing the informed consent forms and completing the questionnaires.

For family and non-family members that are interested in participating, we ask that you read and sign two of the attached consent forms and complete the questionnaires or contact us at the address below. If you enroll, you may be asked to consent to our obtaining your medical records and speaking with your physician. We may also interview you at your convenience over the telephone. We will ask for 2-4 tablespoons of blood to be sent to the Dana-Farber Cancer Institute, to be used for research studies and stored in a sample repository for future use. Buccal samples may be collected once and involve a

swabbing back and forth of the inside of the cheek. If you prefer not to donate buccal and blood samples, you can still participate in the study by signing the informed consent forms and completing the questionnaires.

Please note that we will not share your name or contact information with anyone without your express permission. Also, all information that you provide will be kept confidential (encoded so your identity is concealed).

What are the risks of participating in the study?

The only physical risk will be a slight risk of bleeding or bruising from the site from which your blood is drawn, or pain, redness or black and blue at the needle insertion site from the bone marrow draw. Inflammation or swelling may occur at the site from which your buccal sample is obtained.

Please note that we will not share with you any individual results of this research at any time. The government requires that any test that might provide information to be given to you must be performed in laboratories following certain procedures that research laboratories do not follow.

What will I receive as part of the study?

The study will not be of any direct medical benefit to you. We hope the information learned from this study will benefit other patients with your disease in the future.

What if I want to stop participating in the study?

You may decide to stop participating at any time simply by notifying us in writing. This decision will not affect your medical care in any way. At your request, remaining specimens will be destroyed, and protected health information will be deleted from the database if you decide to stop participating in the study.

How do I participate in the study?

If you are interested, please read and sign two of the attached consent forms and complete the questionnaires. You may mail, fax or scan and email the signed informed consent forms and the dietary questionnaire. The epidemiology questionnaire should be completed electronically. In situations where this is not possible, the questionnaire may be printed for manual completion. An investigator signed, original consent form will be mailed back to you for your own records.

Mailing address:

Irene M. Ghobrial, MD
Dana-Farber Cancer Institute
450 Brookline Ave, D1B30
Boston, MA 02115

Fax: 617-582-7153

Email: DFCItissuebank@gmail.com

Dr. Irene M. Ghobrial, the Principal Investigator of this study, or members of the research staff may contact you with follow-up information after receiving these forms.

Thank you for considering participation in our study.

Any questions?

If you have any questions about this study, feel free to contact Irene M. Ghobrial, MD, at Dana-Farber Cancer Institute, D1B30, 450 Brookline Ave, Boston, MA, 02215 or by e-mail at, DFCIissuebank@gmail.com.

If you have any questions about your rights, responsibilities and protections as a research subject, you may contact the Office for Human Research Studies at Dana-Farber Cancer Institute, at 617-632-3029.