Harvard Study of Genetic Factors that Lead to Lymphoma

What is this study?

The goal of this study is to identify individuals with non-Hodgkin's lymphoma, Hodgkin's disease or CLL/SLL who also have other family members with one of these diseases. We are particularly interested in families in which parents and children or brothers and sisters are both affected with lymphoma. The purpose of the study is to learn more about the genes that contribute to lymphoma by studying members of these families who are interested in participating. Investigators affiliated with the study will use the information you provide, along with blood samples, saliva samples and mouth swabs if you are willing, to conduct research to help increase our understanding of the causes of lymphoma. 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 two or more people in your family have lymphoma and either would like to participate in the study, we ask that you contact us at the email address below. We will send you a family history questionnaire to complete and return. If you are eligible for the study, we will send you a consent form. If you enroll, you will be asked to consent to our obtaining your medical records and possibly speaking with your physician. We may also interview you at your convenience over the telephone. We will ask for a mouth swab, saliva sample and 4 tablespoons (50-60 mL) 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. We may request permission to obtain pathology slides or blocks for further study.

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 that your identity is concealed) so that your confidentiality is ensured.

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. There is a chance that participating in this research could cause emotional distress. Sometimes people feel anxious about possibly carrying an altered gene that could place them or their children at risk of disease. 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 patients and families with lymphoma 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 if you decide to stop participating in the study.

How do I participate in the study?

If you are interested and believe that your family history makes you eligible, please email Conner Shaughnessy at Conner_Shaughnessy@DFCI.HARVARD.EDU. Please include the following information:

- Your diagnosis (type of lymphoma)
- Your family members who have also had lymphoma (i.e. mother, brother, daughter, etc.)
- Please indicate if you are willing to sign a medical release for research purposes and/or willing to donate a blood sample, saliva sample and mouth swab for research purposes
- Your contact information

Dr. Jennifer Brown, the principal investigator of this study, or members of the research staff will contact you with more information about the study.

Thank you for considering participation in our study.

Any questions?

If you have any questions about this study, feel free to contact Conner Shaughnessy or Jennifer R. Brown, MD, PhD, Lymphoma Program, Department of Medical Oncology, Dana-Farber Cancer Institute, LG100, 450 Brookline Ave, Boston, MA, 02215 telephone 617-582-8437, email noted above. If you have any questions about your rights, responsibilities and protections as a research subject, you may contact the Office for Protection of Research Subjects at Dana-Farber Cancer Institute, at 617-632-3029.