

### **WHY IS THIS RESEARCH STUDY BEING DONE?**

The purpose is to learn more about causes of cancer, including inherited genetic factors and genetic changes in tumor cells. This knowledge is necessary for improved and personalized strategies for prevention, early detection, and treatment of cancer.

### **WHY AM I BEING INVITED TO PARTICIPATE?**

You are being asked to participate because:

- You have or have had cancer; or
- You are thought to have an increased risk for cancer;
- You are thought to be at average risk for cancer, and your specimen and information will be used as a comparison to participants at increased risk for cancer.

### **DO I HAVE TO PARTICIPATE?**

No. Taking part in research is always voluntary. If you decide to participate, you may withdraw at any time. If you decide not to participate or begin the study and withdraw later, this will not affect the care you receive in any way.

### **WHAT IS INVOLVED IN PARTICIPATING?**

- You will be asked to provide medical history and family history information and to allow us access to your medical records for cancer and related conditions.
- You will be asked to allow us to obtain stored tissue samples related to cancer.
- You will be asked to provide at most six tubes of blood (4 Tablespoons) and cell lines may be made from the blood specimen you provide.
- You may be asked to assist us in contacting members of your family for research and you may decline to give this permission.
- You may be asked to allow us access to medical records and stored specimens for relatives who are deceased.

- If you choose to, you may provide contact information for someone to receive results in case researchers are unable to reach you.

### **WHAT TYPES OF RESEARCH TESTING MIGHT BE DONE ON MY SPECIMEN(S)?**

We would like to use a wide variety of study methods including DNA tests on tumor and blood specimens that look for differences related to health and disease. Some research tests focus on a single gene, and others give information about many, many genes at the same time. As new tests become available, we will include these as appropriate.

Some of the questionnaire information, specimen(s), and genetic information from you may be shared with other researchers, but it will not contain your name or other identifying information. There are safeguards in place to protect your privacy.

### **WHAT ABOUT CONFIDENTIALITY?**

We will take measures to protect the privacy of all of your personal information. Information from this study will be stored in your study file and a research database. The results of this research study may be published. You will not be identified in publications.

### **WILL I LEARN THE RESULTS OF THE STUDY?**

We anticipate that return of individual results will be relatively rare. Therefore, we will not contact you with individual study results unless they are thought to be directly important for your health and medical care or that of your relatives.

Modern genetic testing technologies are very comprehensive. Even though cancer is the focus of this study, it is possible that information related to *other* medical conditions could be found. Again, we would contact you regarding these 'incidental' findings only if they are thought to be important for your health and medical care or that of your relatives.

It is possible that no individual results will be found or returned to you through your research

participation. This could be due to lack of opportunity to have your specimen analyzed and/or the absence of findings thought to be important for your health or that of your family.

### **WHAT ARE THE RISKS OF THE RESEARCH STUDY?**

Having blood drawn may cause some discomfort.

There is a chance that research participation could cause emotional distress for you or a family member including feeling anxious about the possibility of increased risk for cancer or another condition. We can arrange for you to speak with a genetic counselor to help you make an informed decision about participating in this study or a psychologist if you need support.

Although we have put many safeguards in place, there is a small possibility that your confidentiality could be breached.

### **WHAT ARE THE COSTS?**

No charges will be billed to you or your insurance company for this study.

### **WHAT IF I HAVE QUESTIONS?**

Please call Dr. Judy Garber (DFCI) at 617-632-2282, Dr. Nadine Tung (BIDMC) at 617-661-7081, Dr. Leif Ellisen (MGH) at 617-724-1971, Dr. Karen Krag (MGH/NSCC) at 978-882-6060, Dr. Susan Sajer (MGH/EH) at 978-287-3436, Dr. Junne Kamihara at 617-632-3044 (BCH), or the Office for Human Research Studies at 617-632-3029 and refer to this study, Hereditary and other Risk Factors for Cancer.

### **THIS IS WHAT I AGREE TO:**

By participating in the study, you agree to allow researchers to collect and use the following for study purposes:

- a blood, saliva, or cheek cell specimen
- your medical records related to the study
- cancer-related studies such as MRI and CT scans and laboratory results