CANCER RESEARCH STUDY

What if I agree to participate and change my mind later?
If you decide you no longer want to participate, you will need to notify the Yale Principal Investigator in writing and your specimens and data will not be used for further research.

Mailing Address:
Lajos Pusztai, MD, DPhil
Yale Cancer Center
PO Box 208327
New Haven, CT 06520
Phone: (203) 737-8309

The stored tissue and associated data will be destroyed. However, deserialized samples, which have been distributed to other researchers, research results, and information generated before your withdrawal cannot be located and will not be discarded.

Will I learn the findings from my samples?
In general, we do not plan to contact you or your doctor about research findings from your samples or put the findings in your medical record.

What are the risks of participating?
There is no physical risk involved with banking leftover tissues.

There is a risk that, despite our efforts, your personal information could be revealed to others. Genomic data (i.e., DNA sequences) from cancer and normal tissues that researchers may place in scientific databases could reveal genetic relationships between individuals and could even identify a person.

Germline genomic information may cause concern, including discrimination by others, including employers and insurance companies, and psychological distress. There is a federal law called the Genetic Information Nondiscrimination Act of 2008 (GINA), which makes it against the law for health insurers to request, require, or use genetic information to make decisions about your eligibility for health insurance or your health insurance premium, contribution amounts, or coverage terms. GINA makes it illegal for employers with more than 15 employees to discriminate against you based on your genetic information.

Will I benefit from participating?
Participating is not likely to help you but what we learn could help future patients. Research using your specimens may lead to the development of new tests, new therapies, or products that are sold. You will not receive any money from such sales.

Will it cost me anything to participate?
No. There are no costs involved for you.

What if I have questions?
If you have any questions, please talk with your doctor first or contact Yale Cancer Center at (203) 785-5702. If you have questions about your privacy rights, please contact the Yale Privacy Officer at (203) 432-5919. You can also contact the Principal Investigator of this research, Dr. Lajos Pusztai at (203) 737-8309 or the Yale University Institutional Review Board (IRB) at (203) 785-2190.
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What is research?
Research is the process of creating new knowledge. Clinical and medical research discovers new knowledge about diseases to find better treatments and to develop new diagnostic tests.

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How will my personal information be protected?
Only personnel who are responsible to store, collect and select tissues for research, often called tissue banking, will know which tissue belongs to what person. When tissues or data are given to a scientist for research, your name and any personal identifiers will be removed and will be replaced with a code.

All individuals who may use your specimens or data had training in protection of personal information and fairness in research.

What will my samples be used for?
• Your samples may be used to understand blood samples.
• Your samples may be used to understand normal tissues.

Will samples be kept or will they be used up? Samples will not be kept. Use of your samples will be approved by the Institutional Review Board of Yale University and Yale New Haven Health System (YNHHS).

Who will pay for this research?
Research costs will be paid by the Clinical Research Office of Yale University and Yale New Haven Health System (YNHHS).

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There is a risk that, despite our efforts, your personal information could be revealed to others. Genomic data (i.e. DNA sequences) from cancer and normal tissues that researchers may place in scientific databases could reveal genetic relationships between individuals and could even identify a person.

Germline genomic information may cause concern, including discrimination by others, including employers and insurance companies, and psychological distress. There is a federal law called the Genetic Information Nondiscrimination Act of 2008 (GINA), which makes it against the law for health insurers to request, require, or use genetic information to make decisions about your eligibility for health insurance or your health insurance premium, contribution amounts, or coverage terms. GINA makes it illegal for employers with more than 15 employees to discriminate against you based on your genetic information.

Will I benefit from participating?
Participating is not likely to help you but what we learn could help future patients. Research using your specimens may lead to the development of new tests, new therapies or products that are sold. You will not receive any money from such sales.

Will it cost me anything to participate?
No. There are no costs involved for you.

What if I have questions?
If you have any questions, please talk with your doctor first or contact Yale Cancer Center at (203) 785-5702. If you have questions about your privacy rights, please contact the Yale Privacy Officer at (203) 432-5919. You can also contact the Principal Investigator of this research, Dr. Lajos Pusztai at (203) 737-8309 or the Yale University Institutional Review Board (IRB) at (203) 785-2190.