Tissue Banking
Advancing Cancer Care
Acknowledgments

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About This Program

THIS AUDIOVISUAL PROGRAM AND BOOKLET were produced by Dana-Farber Cancer Institute in collaboration with Brigham and Women’s Hospital, Massachusetts General Hospital, and the Beth Israel Deaconess Medical Center. They are for use by the Dana-Farber/Harvard Cancer Center and other institutions that provide information about tissue banking. Funding for the production of this program was provided by the National Institutes of Health (NIH) Human Subjects Research Enhancements Program.

We thank the patients, family members, and hospital staff members who generously volunteered their time to participate in this program. They described unique experiences in their own words, and their insights provided the core of the program. We also thank the Patient and Family Advisory Council of Dana-Farber Cancer Institute, who offered critical suggestions throughout the production process.

We dedicate this program and booklet to the patients who have donated tissue for medical research.
Our Goal

THIS PROGRAM WAS CREATED TO EXPLAIN WHAT tissue banking is, why it is so important, and who benefits from it. Our goal is to provide information that might help you decide whether or not to donate your tissue for medical research. The booklet reviews key information from the program and answers additional questions you might want to ask.

We hope that this information is useful as you consider whether or not to participate in tissue banking. This booklet is not intended as a substitute for discussions between you and your physician or health care provider.
## Table of Contents

6  WHAT IS TISSUE BANKING?
8  WILL DONATING MY TISSUE CHANGE MY SURGERY OR CARE?
9  WHO BENEFITS FROM TISSUE BANKING?
11  HOW MUCH PERSONAL AND MEDICAL INFORMATION SHOULD I SHARE?
12  HOW WILL MY PRIVACY BE PROTECTED?
14  OTHER QUESTIONS YOU MIGHT WANT TO ASK
14  What are the financial implications of tissue donation?
14  What if I change my mind after donating tissue?
15  Will I get the results of research using my tissue?
15  Will research results be shared with my employer or health insurance provider?
15  Will research using my donated tissue contribute to my medical care?
16  How do I decide whether or not to donate tissue?
17  TO LEARN MORE
Tissue banking is storing leftover human tissue that has been removed during a medical procedure such as an operation, a biopsy, or a blood test. This extra tissue is not needed for your diagnosis or treatment. With your written consent, this tissue is sent to a tissue bank, where it is carefully preserved and protected. Scientists use tissues from these banks to study disease and find better ways to diagnose, prevent, and treat cancer in the future. Tissue donated for medical research is not used in either organ transplantation or blood transfusions.

Human tissue donated for medical research can include:

- Pieces of tumor from the lung, breast, kidneys, or other organs
- Cancerous cells from blood and bone marrow
- Excess normal tissue from organs or blood
- Other fluids from the body
Tissue banking helps scientists better understand what causes cancer, which treatment options are likely to be effective, and how to improve patient care in the years to come.

“Tumor banking is what will take us to the next level of cancer treatment and cure.”

—JUDY GARBER, MD, MPH, PHYSICIAN
PATIENTS SOMETIMES ASK IF THEIR DECISION TO donate tissue will affect their treatment. The answer is no. Regardless of whether you decide to donate your tissue or not, your operation and medical care will be exactly the same. Your decision will not affect how much tissue is removed during surgery, and it will not change the number of visits to your doctor.

Patients who are thinking of donating tissue may also be concerned that the doctor will not have enough tissue for their diagnosis and treatment. That never happens. During your medical procedure, your doctor will remove all the tissue needed for a thorough diagnosis and treatment. A portion of your tissue is not needed for your cancer care. This leftover tissue, which would otherwise be discarded, is sent to the tissue bank.

“We make sure that we have enough tissue to tell us all the information that we need to take care of you, the patient, prior to donating some tissue to a tissue bank.”

—LAWRENCE N. SHULMAN, MD, PHYSICIAN
Who Benefits From Tissue Banking?

If you donate your tissue for research, you probably will not benefit directly, but others will benefit in the future. Tissue banking helps scientists study the biology of cancer. It helps them answer important questions about why cancer develops, how it grows, and who is at risk. The answers to these questions can lead to earlier, more accurate diagnosis and better treatment. But it takes a long time for scientists to make discoveries from medical research. Just as the discoveries of a decade ago led to current therapies, the knowledge gained from studying human tissue today will advance patient care in the years ahead. When you donate your tissue for research, you are helping the generation of cancer patients to come.

Many different types of research rely on the use of human tissue:

- Learning how cancer cells work
- Identifying the causes of cancer
- Understanding how cancer behaves in different ethnic groups
- Developing new cancer drugs and diagnostic tests
- Discovering “markers” that predict who will respond to treatment
For example, by studying thousands of breast tumors, researchers discovered that about 25% carry extra copies of a gene called HER2. This type of breast cancer is known as HER2-positive, and it behaves differently than other breast cancers. After analyzing HER2-positive tumors, scientists were able to develop diagnostic tests, which are now commonly used to find out whether a breast tumor is HER2-positive or not. Knowledge of HER2-positive tumors also enabled scientists to design a drug that slows the growth of tumors and improves survival outcomes for these patients.

“I feel wholeheartedly that I was able to contribute to someone being healed, or cured, or treated.”

—BRENDA, PATIENT
How Much Personal and Medical Information Should I Share?

IT IS YOUR CHOICE WHETHER OR NOT TO DONATE your tissue to a tissue bank. You also have a choice as to how much or how little information you want to share. For example, you can consent just to having your tissue collected. Or you can consent to sharing some personal information such as your gender, age, racial or ethnic group, and history of smoking. You can also allow access to your medical record. The choice is yours.

Knowing a patient’s age and ethnic group may help researchers understand how these factors affect the risk of getting cancer. And being able to study patients’ tissues in light of their medical histories may tell scientists a lot more about the causes of cancer and how to develop new therapies.

“It adds enormous value to the banked tissue if it is linked to some clinical information. You might say, ‘You can have my tissue, you can have access to my medical record, and you can phone me up in 10 years to see how I’m doing.’ Or you can just say no. It’s completely voluntary.”

—CHRISTOPHER FLETCHER, MD, PATHOLOGIST
How Will My Privacy Be Protected?

FEDERAL LAWS AND REGULATIONS PROTECT THE privacy and confidentiality of your medical information. The administrator of the tissue bank must submit a plan explaining how your private information will be protected. A committee at your hospital, known as the Institutional Review Board, or IRB, will review the plan to make sure that it strictly follows these laws and regulations.

The plan must explain what information will be stored in the bank and how it will be kept confidential, how tissues will be collected and linked to confidential information, and how the bank will prevent unauthorized access to its computer files. So the risk of your privacy being violated is very small.

“There's always a finite risk that information will get disclosed. But the benefit of being able to connect her type of tumor with the type of treatment that's successful not only benefits her, if she has a recurrence, but all those other people down the road.”

—ROBIN, PARENT OF PEDIATRIC PATIENT
The IRB must also review the plan if the tissue bank intends to send tissue samples to other researchers for study. Before sending out your tissue sample, the tissue bank will code it with a number instead of your name and take out all identifying information, such as your name, address, phone number, and Social Security number. The tissue bank will include only the information that is needed for the researcher to perform the study.

Before tissue banks and other researchers can use your tissue for study, they must obtain your written consent. This informed consent form explains:

• How your tissue will be collected and used in research
• How your medical information will be stored
• What information will be provided to researchers
• How to contact the tissue bank administrator if you would like to withdraw your consent for future research

By signing the informed consent form, you indicate that you understand the information explained to you and are willing to donate tissue for research purposes.
Other Questions You Might Want to Ask

What are the financial implications of tissue donation?

There is no charge to you or to your insurance company for donating your tissue. At the same time, you will not be paid a fee for your tissue or for any of the discoveries that might result from research using your tissue.

What if I change my mind after donating tissue?

You can change your mind at any time about allowing your tissue to be used in future research. The consent form explains how to contact the tissue bank. If you wish to withdraw your consent for all research or change the amount of personal information you are willing to share, tell the administrator. If some of your tissue has already been sent out, however, the tissue bank cannot get it back, and you cannot withdraw your permission for the research done on those particular tissue samples.
Will I get the results of research using my tissue?

Tissue banks and other researchers will not report to you the results of any research using your donated tissue. Research studies take many years and require tissue samples from hundreds or thousands of people. The results are published in scientific journals.

Will research results be shared with my employer or health insurance provider?

Results of research using your tissue will not be put in your medical record and will not be released to your employer, health insurance provider, or anyone else.

Will research using my donated tissue contribute to my medical care?

The results of research using tissue samples will not affect your care right now. If your cancer comes back in the future, however, new treatment options may be available.
How do I decide whether or not to donate tissue?

Talk it over with your doctor or nurse. Or discuss this booklet with your family and friends. For additional information, see the resources listed on the following page.
To Learn More

For additional information about tissue banking
National Cancer Institute (NCI)
http://www.cancer.gov/clinicaltrials/resources/providingtissue
http://biospecimens.cancer.gov/basics/

BioBankCentral
email: info@biobankcentral.org
http://www.biobankcentral.org/index.php

To view this program using the Internet
http://www.dana-farber.org/tissue_banking

To request a copy of this program
Dana-Farber/Harvard Cancer Center
Office for the Protection of Research Subjects
Dana-Farber Cancer Institute
44 Binney Street
Boston, MA 02115
1 (617) 632-3029
email: oprs@dfci.harvard.edu
http://www.dana-farber.org/tissue_banking
My Questions

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Dana-Farber Cancer Institute
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