

NON-TRANSPLANT TISSUE BANK (Biobank)

RESEARCH CONSENT SUMMARY

The Non-Transplant Tissue Bank (Biobank) is an effort of Stony Brook Medicine and Stony Brook Cancer Center in its commitment to research cancer and other diseases.

The purpose of this tissue bank is to store samples of blood, tissue, and body cavity fluid (i.e. fluid from your chest or abdomen) in special freezers, so they can be made available in the future, to researchers in their study of cancer and other diseases.

Either you are about to undergo, or you have recently undergone, a medically indicated diagnostic or therapeutic procedure/surgery in the hospital. In either case your surgeon is asking permission to store in the Biobank, a sample of your tissue and, if collected, blood taken before surgery and body cavity fluid taken during surgery.

The Biobank is located in the Anatomic Pathology Laboratories at Stony Brook University Hospital. All personal information will be fully protected and will not be disclosed. If you have any questions about the Stony Brook Medicine Biobank, you may contact the Department of Pathology or the Principal Investigator, Dr. Kenneth Shroyer, at 631-444-3000.

FREQUENTLY ASKED QUESTIONS

1. What is the purpose of this study?

- The purpose of this tissue bank is to store samples of blood, tissue, and body cavity fluid in special freezers, so they can be made available in the future for research in the study of cancer and other diseases.

2. What are the risks/discomforts involved?

- There are no foreseeable risks or discomforts associated with your participation in this study.
- Although the Biobank uses coded identifiers that are kept in a secured computer database, there is always the possibility of a loss of confidentiality. Despite all of the safety measures that we will use, we cannot guarantee that your identity will never become known, but we believe this possibility is very small.

3. How do I benefit from this?

- There is no benefit to you expected as a result of your being in this study. The results obtained from any research done on your tissue, body cavity fluid/blood will not affect your medical care, will not be placed in your medical record, nor made available to your doctor. It may help people with diseases in the future.

4. Is there a fee or payment to me?

- You will not be paid for your participation. There is no fee for participation. Your tissue/blood will only be used for research and will not be sold.

5. What about privacy? Is this confidential?

- We will take steps to help make sure that all the information we obtain is kept private. Your name will not be used wherever possible. We will use a code instead. All the study data that we get from you will be kept locked up. The code will be locked up too. If any publications or talks are given about this research, your name will not be used.
- Investigators who perform research on your tissue may be required to send information they obtain about your health and your genes to one of the federal National Institutes of Health databases or repositories, so it can be used in future research along with similar information from other research participants. Preserving the confidentiality of your information is very important to us, and we will do so by removing any information that can identify you (like your name), and instead, assign a code to your medical information and the information we obtain from your tissue samples before we send that information to one of the National Institutes of Health databases or repositories. Stony Brook will keep the master list that links your code number to your identifying information and only certain Stony Brook research staff members will ever have access to this master list.
- We want to make sure that this study is being done correctly and that your rights and welfare are being protected. For this reason, we will share the data we get from you with the study team, Stony Brook University Committee on Research Involving Human Subjects, applicable Institutional officials, and certain federal offices.

6. What if I choose to withdraw from the study, who do I contact?

- You have the right to stop allowing us to use or give out your tissue, blood and body cavity fluid samples for further research. You can do this at any time by writing to Dr. Kenneth Shroyer, Department of Pathology, Stony Brook University, Stony Brook NY 11794-8691. If you contact us and let us know in writing, then any of your samples that remain in the tissue bank will be destroyed and will not be used in research. However, any de-identified samples already in use at that time will continue to be used by researchers.

7. What are my Rights?

- Your participation in this study is voluntary. You do not have to be in this study if you don't want to be.
- You have the right to change your mind and leave the study at any time without giving any reason, and without penalty.
- Any new information that may make you change your mind about being in this study will be given to you.
- You will get a copy of this consent form to keep.
- You do not lose any of your legal rights by signing this consent form.