

# RESEARCH ASSENT FORM

# (Minor Subjects)

#### You are being asked to be in a research study.

#### Purpose

The purpose of the Non-Transplant Tissue Bank (Biobank) is to store tissue, blood and body fluid samples in special freezers. In the future, researchers can get permission to use these samples in their study of cancer and other diseases.

#### What Will Be Done

If you agree to be in this study, you will be asked to:

- Allow an additional blood sample to be taken (about 15 ml or one tablespoon) when you have your pre-surgery tests done. The sample will be stored in the Biobank for future research. (Note: a blood sample will be taken only if you sign this Assent before you have your procedure.)
- Allow any leftover tissue that remains after all the necessary medical tests are done, to be stored indefinitely in the Biobank for future research.
- Allow any leftover body fluid that remains after all the necessary medical tests are done, to be stored indefinitely in the Biobank for future research.
- Allow your medical record to be linked (via a code) with your blood, tissue and body fluid samples. Researchers will not be able to identify you.

# Costs to You

You will not have to pay anything to be in this study.

#### Payments to you

You won't get paid for being in this study. Your samples will only be used for research and will not be sold.

## Risks/Discomforts

- There are no foreseeable risks or discomforts associated with your participation in this study.
- In the future, if your samples are given out for research, they will be de-identified. This means that no one will be able to find out you donated the samples to the Biobank.

## **Benefits**

- There are no direct benefits to you from participating in this study.
- Results obtained from any research done on your samples will not affect your medical care, they will not be placed in your medical record, and will not be given to your doctor.
- Research on your samples may help people with cancer or other diseases in the future.

#### Removal from the Study

You or your parents can have your samples removed from the Biobank at any time. If you or your parents write Dr. Shroyer to tell him you don't want your samples to be used for research anymore, then they will be removed from the Biobank and destroyed. However, any samples that are already being used in a research project will continue to be used.

#### Your Rights

- The fact that you are in this study will be kept a secret.
- You don't have to be in this study if you don't want to be.
- You can change your mind at any time and leave the study without any problem and without telling us why.
- If we find out anything that may make you change your mind about being in this study, we will tell you.

#### Questions

- If you have any questions about this study, you can ask your parents, or talk to the study doctor, Dr. Kenneth Shroyer, at 631-444-3000.
- If you want to talk to someone about whether or not you have to be in this study, or about other things about this study that you don't want to talk over with your parents or the study doctor, you can call the Stony Brook University Research Subject Advocate, Ms. Lu-Ann Kozlowski, BSN, RN, 631-632-9036, OR by e-mail <u>lu-ann.kozlowski@stonybrook.edu</u>
- You can visit Stony Brook University's Community Outreach webpage at <a href="http://www.stonybrook.edu/research/orc/community.shtml">http://www.stonybrook.edu/research/orc/community.shtml</a> for information about being in research studies and read frequently asked questions. You can also ask questions or leave comments about how you feel about being a research subject in this study.

If you sign below, it means that you have read this form and you would like to be in this study.

Subject Name (Printed)

Subject Signature

Name of Person Obtaining Assent (Printed)

Signature of Person Obtaining Assent

Date