NCI Community Oncology Research Program – Kansas City

Authorization (Permission) to Use or Disclose (Release)
Identifiable Health Information for Research

Participant's Name: ____

Participant's Address: ____

Birth Date: ____

Study Number & Title: ____

1. What is the purpose of this form?

The **NCI Community Oncology Research Program – Kansas City (NCORP-KC)** is an organization that does research to learn about the causes of cancer, and how to prevent and treat cancer. Researchers would like to use your health information for research. This information may include data that identifies you. Please carefully review the information below. By signing this form, you authorize any health plan, physician, health care professional, hospital, clinic, laboratory, pharmacy, medical facility, or other health care provider that has provided payment, treatment, or health care services to you or on your behalf to disclose your personal health information to the Cooperative Group for the purposes stated herein. If you agree that researchers can use your personal health information, you must sign and date this form to give them your permission.

2. What personal health information do the researchers want to use?

The researchers want to copy and use the portions of your medical record that they will need for their research. If you enter a **Cooperative Group** research study, information that will be used and/or released may include the following:

- the history and diagnosis of your disease;
- specific information about the treatments you received, including previous treatment(s) you may have had;
- information about other medical conditions that may affect your treatment;
- medical data, including laboratory test results, tumor measurements, CT scans, MRIs, x-rays, and pathology results;
- information on side effects (adverse events) you may experience, and how these were treated;
- long-term information about your general health status and the status of your disease;
- data that may be related to tissue and/or blood samples that may be collected from you; and

- numbers or codes that will identify you, such as your social security number and medical record number.

You may request a blank copy of the **Cooperative Group** data forms from the study doctor or his/her research staff to learn what information will be shared.

This permission form does not apply to psychotherapy records. If psychotherapy records are to be released, a separate and specific permission form must be used.

3. Why do the researchers want my personal health information?

The NCORP-KC will collect your health information and share it with the **Cooperative Group** Biostatistical Center and the **Cooperative Group** Operations Center if you enter a cooperative group research study. The **Cooperative Group** centers will use your information in their cancer research study.

4. Who will be able to use my personal health information?

The NCORP-KC will use your health information for research. As part of this research, they may give your information to the following groups taking part in the research. NCORP-KC may also permit these groups to come in to review your original records that are kept by NCORP-KC so that they can monitor their research study.

- the **Cooperative Group** Operations Center;
- the **Cooperative Group** Biostatistical Center;
- the Clinical Trials Support Unit (CTSU), a research group sponsored by the National Cancer Institute that supports the research of the **Cooperative Group;**
- Public Health agencies and other government agencies (including non-U.S.) as authorized or required by law;
- other people or organizations assisting with **Cooperative Group** research efforts (this may include a pharmaceutical company[ies] or designee[s], and any subcontractors), and
- central laboratories, central review centers, and central reviewers. The central laboratories and review agencies may also give your health information to those groups listed in the five bullets above.

5. How will information about me be kept private?

The **Cooperative Group** will keep all patient information private to the extent possible, even though the **Cooperative Group** is not required to follow the federal privacy laws. Only researchers working with the **Cooperative Group** will have access to your information. The **Cooperative Group** will not release personal health information about you to others except as authorized or required by law. However, once your information is given to other organizations that are not required to follow federal privacy laws, we cannot assure that the information will remain protected.

6. What happens if I do not sign this permission form?

If you do ot sign this permission form, you will not be able to take part in the research study for which you are being considered.

7. If I sign this form, will I automatically be entered into the research study?

No, you cannot be entered into any research study without further discussion and separate consent. After discussion, you may decide to take part in the research study. At that time, you will be asked to sign a specific research consent form.

8. What happens if I want to withdraw my permission?

You can change your mind at any time and withdraw your permission to allow your personal health information to be used in the research. If this happens, you must withdraw your permission in writing.

Beginning on the date you withdraw your permission, no new personal health information will be used for research. However, researchers may continue to use the health information that was provided before your withdrew your permission.

If you sign this form and enter the research study, but later change your mind and withdraw your permission, you will be removed from the research study at that time.

To withdraw your permission, please contact the person below. She will make sure your written request to withdraw your permission is processed correctly.

Leslie Herst, Executive Director
NCI Community Oncology Research Program – Kansas City (NCORP-KC)
4121 W. 83rd Street, Suite 259
Prairie Village, KS 66208
(913) 948-5588 Phone
(913) 948-5589 Fax

9. How long will this permission last?

If you agree by signing this form that researchers can use your personal health information, this permission form has no expiration date and continues in effect unless and until you withdraw your permission in accordance with Section 8 above.

10. What are my rights regarding access to my personal health information?

You have the right to refuse to sign this permission form. You have the right to review and/or copy records of your personal health information kept by NCORP-KC. You do not have the right to review and/or copy records kept by the **Cooperative Group** or other researchers associated with the research study.

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Signatures

I agree that my personal health information may be used for the research purposes described in this form.

Signature of Patient
or Patient's Legal Representative: ____ Date: __________

Printed Name of Legal Representative (if any): ____

Representative's Address: ____

Representative's Phone Number: ____

Representative's Authority to Act for Patient: ____

Signature of Person Obtaining Permission: ____________________________________ Date: _________

Printed Name of Person Obtaining Permission: ____