

UNIVERSITY OF WASHINGTON

AUTHORIZATION TO USE, CREATE AND SHARE HEALTH INFORMATION FOR RESEARCH FOR PROJECT ENTITLED, PRO RECD SEP 18 2007 **"Repository of Data and Specimens for Merkel cell carcinoma Research "** **[Paul Nghiem, MD, PhD, University of Washington / FHCRC, 206-221-4594]**

By law, researchers must protect the privacy of health information about you. In this form the word "you" means both the person who takes part in the research and the person who gives permission for another person to be in the research. Researchers may use, create, or share your health information for research **only if you let them**. This form describes what researchers will do with information about you. Please read it carefully. If you agree with it, please sign your name at the bottom. You will get a copy of this form after you have signed it.

If you sign this form, health information about you will be shared with the people who conduct the research. In this form, all these people together are called "researchers." Their names will appear on the research consent form that you sign.

The researchers will use the health information only as described in the research consent form that you sign.

1. What "health information" includes

- Information about you that is created during the research study. This might include the results of tests or exams that become part of the study records, diaries and questionnaires that you might fill out as part of the study, and other records from the study.
- Information in your medical record that is needed for this research study. This might include the results of physical exams, blood tests, x-rays, diagnostic and medical procedures and your medical history.

2. What the researchers may do with health information

The researchers may use and create health information about you for the study. They may also share your health information with certain people and groups. These may include:

- The sponsor of the study, NCI, and its representatives.
- Government agencies, regulators, review boards, and others who watch over the safety, effectiveness, and conduct of the research. These may include such groups in the US and in other countries.
- Other researchers when a review board approves the sharing of the health information.
- Your health insurer if they are paying for care provided as part of the research study.
- Others, if the law requires.

3. Removing your name from health information

The researchers may remove your name (and other information that could identify you) from your health information. No one would know the information was about you.

If the identifiers are removed, the information may be used, created, and shared by the researchers and sponsor as the law allows. (This includes other research purposes.)

This form would no longer limit the way the researchers use, create, and share the information.

4. How the researchers protect health information

The researchers [and sponsor] will follow the limits in this form. If they publish the research, they will not identify you unless you allow it in writing. These limitations continue even if you take back this permission.

5. After the researchers learn health information

The limits in this form come from a federal law called the Health Insurance Portability and Accountability Act. This law applies to your doctors and other health care providers.

Once the researchers and others who are not your doctors and health care providers get your health information, this law may no longer apply. But other privacy protections will still apply.

6. Storing your health information

Your health information may be added to a database or data repository. This permission will end when the database or data repository is destroyed.

7. Please note

You do not have to sign this permission (“authorization”) form. If you do not, you may not be allowed to join the study. You may change your mind and take back your permission at any time. To take back your permission, write to: Paul Nghiem, MD, PhD, 815 Mercer St., Seattle, WA 98109. If you do this, you may no longer be allowed to be in the study. The researchers will keep any information about you they have already collected.

During the study, you will not be allowed to see your health information that the researchers may place in your medical record. After the study is finished, you may see this information.

8. Expiration

This permission will expire when the purposes of the study have been met. This will happen no later than the termination of the Repository.

9. Your signature

I agree to the use, creation, and sharing of my health information for purposes of this research study

Signature of research subject or subject’s legal representative

Date

Printed name of research subject or subject’s legal representative

Representative’s relationship to subject