

For the Use of Patient Health Information for Research

Research Title: University of Washington Neuropath Core, Brain Aging and
Neurodegeneration Brain Bank
Lead researchers: Thomas J. Montine, MD, PhD & Joshua Sonnen, MD
Institution of lead researchers: University of Washington

RECEIVED
Human Subjects Division

JAN 05 2012

A. Purpose of this form

The purpose of this form is to give your permission to the research team to obtain and use your patient health information. Your patient information will be used to do the research named above.

This document is also used for legally-authorized representatives of subjects (such as an appropriate family member) to provide permission to obtain patient information of individuals who are not capable themselves of providing permission. In such cases, the terms "you" and "your patient information" refer to the subject rather than the person providing permission.

State and federal privacy laws protect your patient information. These laws say that, in most cases, your health care provider can release your identifiable patient information to the research team only if you give permission by signing this form.

You do not have to sign this permission form. If you do not, you will not be allowed to join the autopsy and tissue donation program. However, your decision to not sign this permission will not affect any other treatment, health care, enrollment in health plans or eligibility for benefits, or your enrollment as a research participant in your clinical research study.

B. The patient information that will be obtained and used

"Patient information" means the health information in your medical or other healthcare records. It also includes information in your records that can identify you. For example, it can include your name, address, phone number, birth date, and medical record number.

1. Location of patient information

By signing this form you are giving permission to the following organization(s) to disclose your patient information to the autopsy and brain donation program.

- UW Medicine (includes University of Washington Medical Center & Clinics; Harborview Medical Center & Clinics; UW Medicine Neighborhood Clinics; University of Washington Sports Medicine Clinic; UW Medicine Eastside Specialty Center; Hall Health Primary Care Center; University of Washington Physicians)

2. Patient information that will be released for research use

This permission is for the health care provided to you during the following time period: from the time of onset of your neurological symptoms until completion of your autopsy. The specific information that will be released and used for this research is described below:

- Hospital discharge summary
- Radiology records
- Medical history / treatment
- Consultation
- Radiology films (like X-rays or CT scans)
- Laboratory / diagnostic tests
- EKG report
- EEG report
- Psychological testing

C. How your patient information will be used

The researcher will use your patient information only in the ways that are described in the research consent form that you sign and/or as described here. The research consent form describes who will have access to your information. It also describes how your information will be protected. You can ask questions about what the research team will do with your information and how they will protect it. The privacy laws do not

always require the receiver of your information to keep your information confidential. After your information has been given to others, there is a risk that it could be shared without your permission.

D. Expiration

This permission for the researchers to obtain your patient information ends one year after death.

E. Canceling your permission

You may change your mind at any time. To take back your permission, you must send your **written** request to:

UW NP Core BAND Brain Bank
ATTN: Aimee Schantz, Res Mngr
Campus Box 359645
325 9th Avenue,
Seattle, WA 98104

If you take back your permission, the research team may still keep and use any patient information about you that they already have. But they can't obtain more health information about you for this research unless it is required by a federal agency that is monitoring the research.

If you take back your permission, you will need to leave the autopsy and brain donation program. However, changing your mind will not affect any other treatment, payment, health care, enrollment in health plans or eligibility for benefits, or your enrollment as a research participant in your clinical research study.

F. Giving permission

You give your permission to release your information by signing this form.

To release the specific information listed below, you need to also write your initials next to the type of information. This is your specific permission for release of this information, which is required by Federal and state laws. The federal rules bar any use of the information to criminally investigate or prosecute any alcohol or drug abuse patient.

- _____ Sexually transmitted disease
- _____ AIDS or HIV
- _____ Behavioral or mental health/illness, including psychotherapy notes
- _____ Drug or alcohol abuse, diagnosis, or treatment

Printed Name of Research Subject Birth Date

Signature of Research Subject Date of Signature

Printed Name of Person Authorized to Give Permission

Signature of Person Authorized to Give Permission Date of Signature

Relationship to Subject and Description of Authority

You will receive a copy of this signed form. Please keep it with your personal records.