

APR 26 2011

UW

HIPAA Authorization

For the Use and/or Release of Protected Health Information for Research

Research Title: International Registry of Werner Syndrome/Cell Bank
Lead researcher: George M. Martin, MD
Institution of lead researcher: University of Washington

A. Purpose of this form

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

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

State and federal privacy laws protect your health information. These laws say that, in most cases, your health care provider can release your identifiable health 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 research study. Your decision to not sign this permission will not affect any other treatment, health care, enrollment in health plans or eligibility for benefits.

B. The protected health information that will be obtained and used

"Protected health 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, birthdate, and medical record number.

By signing this form you are giving permission to the following organization(s) to disclose your protected health information for this research.

Name of health care organization(s):

This permission is for the health care provided to you during the following time period: From the onset of premature aging symptoms until the end of this research study.

The specific information that will be released and used for this research is listed below:

- Medical history / treatment
- Consultation
- Radiology films (like X-rays or CT scans)

- Laboratory / diagnostic tests
- EKG report
- EEG report
- Pathology reports

C. How your health information will be used

The researcher will use your health information only in the ways that are described in the research consent form that you sign and as described here.

The privacy laws do not always require the receiver of your information to keep your information confidential. 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.

In all cases, your health information in the research records may be shared with, used by, or seen by

- Employees and agents of the sponsor, the National Institutes of Health, who is paying for the study.
- People from agencies and organizations who watch the safety, effectiveness, and performance of the research.
- Other researchers, when a review board approves the sharing of the health information.
- Your health insurer if they are paying for health care that is part of the research study.
- Others, as required by law.

If any of these people or groups review your research record, they may also need to review the same parts of your original health care record that the research team will see.

D. Expiration

This permission for the researchers to obtain and use your identifiable health information does not expire.

E. Canceling your permission

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

Junko Oshima, MD, PhD
 Research Associate Professor, International Registry of Werner Syndrome
 UW Dept of Pathology Box 357470
 1959 NE Pacific St, Seattle WA 98195

If you take back your permission, the research team may still keep and use any health 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 research study. This means that you would not have any more research treatments or tests. Changing your mind will not affect any other treatment, payment, health care, enrollment in health plans or eligibility for benefits.

F. Permission for information

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

Your health record may have specially protected health information. Put your initials on the line(s) below, if you **don't** want the research team to record or use this specific information.

_____ Sexually transmitted disease

_____ AIDS or HIV
_____ Behavioral or mental health services, including psychotherapy notes
_____ Drug or alcohol abuse, diagnosis, or treatment

Printed Name of Research Subject

Birthdate

Signature of Research Subject

Date of signature

Printed Name of Subject's Representative

Signature of Subject's Representative

Date of signature

Description of Representative's authority to act for subject (for example: parent)

