

**UNIVERSITY OF WASHINGTON
SCHOOL OF MEDICINE
SEATTLE, WA 98195
PROXY CONSENT FORM
INTERNATIONAL REGISTRY OF WERNER SYNDROME
AND OTHER PREMATURE AGING SYNDROMES**

_____, Referring Physician
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INVESTIGATOR'S STATEMENT

We are asking you to be a proxy for your next of kin in consenting for use of their tissue in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to allow the tissue to be used for the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you agree to this use of tissue. This process is called 'informed consent.' We will give you a copy of this form for your records.

PURPOSE AND BENEFITS

The purpose of this research project is to identify genes that cause aging syndromes and to understand how those genes normally function and how abnormal forms of the genes can lead to a number of disorders commonly associated with aging, particularly benign and malignant tumors and cardiovascular disease. We would like to study patients with Werner's Syndrome or other syndromes with symptoms of premature aging and their close family members. The study may be of benefit to you if we learn that there are mutations in the specific genes we will examine because it may provide you with more information about your deceased family member. If they were clinically affected and we are unable to identify an alteration, it may mean that the diagnosis is not correct and additional consultation should be sought. We hope that, by understanding the genetic basis of inherited disorders of aging syndromes, we may someday be able to develop effective treatments and even cures for these disorders. There are currently no available treatments that address the underlying mutational basis of the disease. The results of this study may also lead to new approaches in the prevention and treatment of a number of common disorders in older people.

PROCEDURES

If you agree to use of the sample, we will also ask for permission to allow your family member's physician(s) to obtain information from their medical records in order to complete the Registry Form. This form includes your name and contact information in addition to the subject's personal medical information related to symptoms of Werner syndrome and other progeroid syndromes. We ask for information about immediate family as it related to gender, whether they are living or have died and whether they have any symptoms of premature aging.

If symptoms of your family member are consistent with Werner Syndrome, our laboratory will use the tissue samples to determine if they carried a copy of the mutant gene which, when present in two copies, causes the Werner syndrome. (There are no known clinical abnormalities associated with having only a single copy of the mutant gene.) If there is no change in the Werner gene found, or symptoms are not consistent with Werner syndrome, we will investigate various other candidate genes.

Once the studies are completed on the Werner gene, these results will be shared with the referring clinician and with you if you wish to know, as our laboratory is certified for clinical testing of the Werner gene. Interpretation of the test result in light of your family history can be provided by your physicians, who may consult with Dr. Martin, Dr. Oshima, or Ms. Hanson, a Certified Genetics Counselor. Information on other candidate genes will be shared if clinically relevant, but results should be verified in a laboratory certified for clinical testing.

OTHER INFORMATION

Tissue blocks will be returned to the originating laboratory after testing. We would keep all records (pathology reports) indefinitely. The sample will be used only for research.

The tissue donor's identity will remain confidential. Samples will be coded and not identified by subject's name. Only Dr. Martin, Dr. Oshima, Ms. Hanson and three senior technical associates will have access to patient identities linked with this data. Unidentified cell lines and clinical data may be shared with other non-profit repositories for research on aging. Clinical information will be kept indefinitely in order to investigate new hypotheses concerning the functions of the various gene products associated with aging syndromes.

Medical photographs will be requested of some subjects. Those in which the face or other identifying parts are visible will be marked so as to obscure the identity of the individual if that is the wish of the subject. In some instances those features are the important ones to illustrate, however. Permission for use in medical publication and for illustration of medical lectures will be obtained with a separate release form specific to this research project. The photographs will be retained by the investigators and will be used only for purposes specified by the participant. At any time, the proxy for the subject of the photographs may review them, may withdraw permission for their use, or may delete portions.

Printed name of researcher

Signature of researcher Date

Printed name of referring physician

Signature of referring physician Date

PROXY STATEMENT

This study has been explained to me. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. I will receive a copy of this consent form.

Printed name of subject

Relationship of proxy

Printed name of proxy

Signature of proxy Date

Revised 4/26/04