UNIVERSITY of WASHINGTON
HUMAN SUBJECTS DIVISION

HIPAA Authorization

For the Use of Patient Health Information for Research

Research Title:	Severe Chronic Neutropenia International Registry
Lead researcher:	David C. Dale, 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 patient health information. Your patient information will be used to do the research named above.

This document is also used for parents to provide permission to obtain the patient information of their minor children, and 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 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 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, birthdate, 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 for this research.

Name of health care organization(s) or provider(s):

_____

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 your enrollment into the study through the date when the research ends and any required monitoring of the study is finished.

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

- All records for which you have given permission to be sent to us by your physician

3. Use of the UW Clinical Research Center (CRC)

Some of the research procedures may occur at the UW Clinical Research Center (CRC). In the unlikely event something happens to you that requires treatment while you are at the CRC, information about the event and treatment will also be released to the researcher. Examples: fainting during a blood draw or stumbling while entering the blood draw area.

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 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 on the date when the research ends and any required monitoring of the study is finished.

E. Canceling your permission

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

Audrey Anna Bolyard
Severe Chronic Neutropenia International Registry
University District Bldg
1107 NE 45th St., Suite 345
Seattle, WA 98105

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 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. 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 | Birthdate

_____

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
(Examples: parent of a young child; sister of an individual who is in a coma; researcher who signs for a subject who is unable to physically sign the authorization but was observed by the researcher to read and otherwise agree to the authorization.)

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