

The Severe Chronic Neutropenia International Registry

What is the purpose of this study?

The purpose of this research study is to learn more about the cause and outcome for Severe Chronic Neutropenia (SCN). The objective of the Registry is to collect information on the natural course of SCN and its response to treatment with the blood stimulating factor called granulocyte colony stimulating factor or G-CSF, transplantation of blood forming cells, and other therapies. The Registry also is studying the risk of development of osteoporosis (thin and brittle bones), enlargement of the spleen and other changes that may affect your health including the possibility of developing leukemia.

Who will be included?

You are being asked to take part in this research study because you have been diagnosed with a form of Severe Chronic Neutropenia.

What samples/information do we need?

Bone marrow slides will be collected during this study. Your medical information will also be collected.

What is involved?

As a participant in the Registry, you will have regular medical checkups and tests (blood counts) as prescribed and directed by your physicians. For the Registry, you may be asked to maintain a calendar to record treatments you receive for neutropenia if you are ill or hospitalized. Maintenance of the calendar is voluntary.

To be in the Registry, you and your physician are required to release information regarding your medical history and medical tests to the Registry office at the University of Washington, Seattle, Washington. The Registry requests bone marrow slides that have been done as part of your regular care be sent with the registration information if your health changes significantly. As a participant in the Registry, your doctor will be asked to complete standard forms when you are enrolled and about once a year thereafter for as long as you remain in the Registry. This information will include:

- name
- address
- birth date
- gender
- race
- referring doctor
- diagnosis
- medical history
- medical history of infections and related medical problems
- growth and development markers (for children, e.g., height, weight, milestones of physical and sexual development)
- record of treatments for neutropenia.

Every year that you remain in the Registry, we will ask your physician about your current health status, blood counts, bone marrow tests (if done), and infections or serious illnesses.

What will be done with the samples?

Your samples will be sent to the SCNIR in Seattle, Washington for diagnostic purposes.

Collection and Storage of Personal and Medical Information:

Researchers in this study will gather information about your medical history from your chart. The researchers will also review the chart to obtain information about the bone marrow transplant such as laboratory data, exams and physician progress notes.

The information from the research study may be published; however, you will not be identified in such publication.

What are the benefits?

If you agree to take part in this research study, there will not be a direct medical benefit for you. The information learned from this research study may benefit other patients with an immune disorder in the future.

Will I get all the facts about the study?

If you are interested in participating in this study, you will meet with a study coordinator who will explain all of the details of the study. The study coordinator will review the consent form and will be sure that all questions are answered. The consent form describes all the procedures, risks, benefits and who to contact with questions or concerns. Study procedures will not begin until the consent has been signed by the patient (if over 18 years) or the parent/guardian of the patient.

What are the risks?

A detailed list of possible risks will be provided to those patients interested in knowing more about the study.

Who should I contact for more information?

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