



SCNIR

Severe Chronic Neutropenia International Registry

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INFORMATION FOR MINOR PATIENTS TO PARTICIPATE IN THE REGISTRY

For children older than 12 years

You have been diagnosed with a rare blood disorder by your doctors. In medical language it is called **neutropenia**. Your doctors probably will treat you for a long time, possibly even for your whole life, because of this neutropenia. As you have probably heard, neutropenia is a very rare disease. This means that even in big cities or communities there are only a few people suffering from neutropenia, and therefore many doctors and clinics have never treated a patient with neutropenia.

To gather more information about the disease neutropenia, treatment options and long-term effects of the disease affecting life in childhood and adulthood, a registry, the Severe Chronic Neutropenia International Registry (SCNIR), has been established.

This registry collects medical data from patients with neutropenia and stores it in a computer database. It includes blood counts and bone marrow results, as well as information on how often you suffer from infections or whether antibiotics had to be taken. As a result, a large number of patients can be evaluated and the course of the disease can be compared. Only in this way the physicians and scientists are able to understand and compare the course of the disease and how neutropenia is expected to affect you later on.

What we learn from the registry data can also help you, your family, and your doctors to better understand your condition and to treat you the best way.

With the help of the registry we would like to answer the following questions:

1. How does the treatment of neutropenia affect your later life? Are there treatment side effects that only affect adulthood?
2. Is there an increased risk of developing blood cancer (leukemia) compared to other patients?
3. Is there a new or different treatment option for neutropenia?

We would like to include you in our registry.

However, before you decide to join the registry, you should know the following about participation:

1. Participation is absolutely voluntary.
2. You can change your decision at any time and thus end your participation.
3. If you do not want to participate, you will not face any disadvantages.
4. Before deciding, you can spend as much time as you need to fully educate yourself, and discuss your decision in detail with your doctors, family, or friends.

What will happen if you participate in the registry?

For inclusion in the registry, the following information is required from each patient:

1. **Blood counts and a bone marrow result** confirming that you are suffering from "severe chronic neutropenia" as well as other findings that further describe your condition. These findings will be transferred to the SCNIR.
2. Because you are still a minor patient, we also require an agreement signed by your parents or legal guardian to participate in the registry.

Once registered, a questionnaire will be sent to your family doctor once a year, asking for your further treatment, your current height and weight, and your medical condition over the past year. We also request copies of your blood tests, bone marrow results, and other results from tests performed for your neutropenia.

Your data is encrypted before being entered into the SCNIR database (instead of your name, the data is stored by using a number).

We only ask for the results of examinations that were necessary because of your illness or to monitor your treatment and in any case would be carried out without being registered.

Of course, all results are subject to medical confidentiality and are treated absolutely confidential.

Participation in the SCNIR could be beneficial for you:

We cannot guarantee that you will experience a direct benefit through participation. However, it may be beneficial for your clinical data and test results to be viewed and reviewed by specialists in neutropenia. It may also be an advantage that the SCNIR knows more patients with your condition and can therefore answer questions about the further course of your disorder.

If you would like to participate in the International Registry of Severe Chronic Neutropenia, please sign the separate consent form with your parents.