



SCNIR

Severe Chronic Neutropenia International Registry

European Office

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INFORMATION FOR MINOR PATIENTS TO PARTICIPATE IN THE REGISTRY

For children younger than 12 years

Dear

Your doctors have diagnosed you with a rare blood disorder. With very few people suffering from this condition, many doctors have never seen a child with your condition.

We would like to know more about your blood disorder to better understand this rare condition.

We want to answer the following questions with the help of this registry:

1. How does the treatment of your condition affect your later life? Are there any side effects of your treatment that occur later?
2. Is your risk increased to suffer from another blood disorder (blood cancer)?
3. Is there a new or different treatment option for your blood disorder?

We would like to include you in our registry.

If you agree to participate in our registry, we would like to collect your medical data, like information about how often you were sick and how you felt during the year, your blood counts and medical reports from your doctors' about you. We will contact your doctors regularly to collect this data about you over a long period of time.

What will happen if you participate in the registry?

To be included in our registry, we will need the following:

1. **Blood counts and a report on your bone marrow**, confirming that you are suffering from the blood disorder we are studying.
2. Because you are still a child, we also need an **agreement signed** by your parents or legal guardian to participate in the registry.

Being registered, we will send your doctor a letter once a year, asking questions about your treatment, size and weight. We also ask how you did during the year. We also request copies of your blood counts, bone marrow findings, and other results from tests that have been performed for your blood disorder. We only ask for results from examinations that were necessary because of your illness or to monitor your treatment, and would also be done without participating in our registry.

All the data we ask from your doctors will be encrypted by us. This means that instead of your name, there will be a number on the letters. This will ensure that no outsider can link your information with you. All this is strictly confidential, so we will not talk to outsiders about you and your data.

You can reject the decision to participate in our registry any time. No one can be forced to participate because everything is voluntary. So there are no disadvantages if you do not want to participate in our study. If you change your mind later, let us know, then we will erase all data from you. There are no disadvantages for you. If you have further questions, feel free to contact us. We are happy to answer any questions.

If you would like to participate in the study, we ask you to sign the separate consent form together with your parents. By this you are telling us that you want to participate in the registry, and you know it is voluntary. But you can also say later at any time that you no longer want to participate. In this case you will not have any disadvantages.