

ASSENT TO PARTICIPATE IN THE

**SEVERE CHRONIC NEUTROPENIA
INTERNATIONAL REGISTRY (SCNIR)**

- FOR MINOR PATIENT -

ADDRESS

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Patient Identification: _____

INTRODUCTION

You have been diagnosed with a rare blood disease called **neutropenia** in its medical term. Usually, neutropenia requires treatment over a long time period, possibly a life long. As already mentioned, neutropenia is a very rare disease. This means for you, that even in big cities or communities only few individuals are affected. Therefore, many private and clinical physicians have never seen or treated a patient with neutropenia before.

To collect more information on neutropenia, treatment options and late effects of the disease, which concern your life during adulthood, a disease registry, the SCNIR (Severe Chronic Neutropenia International Registry) was established. This registry collects medical data from patients with neutropenia in an international computer database. The information includes blood counts and bone marrow results, but also information on your health status, e.g. the frequency of febrile infections and whether you needed to take oral antibiotics. With this database a large number of patient data can be analyzed and the course of the disease can be compared. This is the only way physicians and researchers can learn more about neutropenia and long term consequences of this disease.

All we learn from the registry data may help you, your family and your treating physicians to better understand your disease and provide you with optimal treatment. We try to answer the following questions through the registry:

Was wir aus den Registerdaten lernen, kann auch Dir, Deiner Familie und Deinen Ärzten helfen, mit Deiner Erkrankung besser umzugehen und Dich nach den besten Möglichkeiten zu behandeln. Die folgenden Fragen möchten wir mit Hilfe des Registers beantworten:

1. How does the neutropenia treatment influence your future life, especially, do you experience adverse events, which may effect you during adulthood only?
2. How is your individual predisposition to leukemia compared to other patients?
3. Are there new or different treatments available for your type of neutropenia?

We would appreciate your participation into the registry very much.

Before you decide on the participation in the registry, you should be aware of the following:

1. Participation is entirely voluntary.
2. You may choose not to take part or you may withdraw your participation in the SCNIR at any time.
3. Before you decide to join the SCNIR, please take as much time as you need to ask all questions and discuss your decision with your physicians, your family or with friends.

What happens, if you decide to participate in the Registry?

For **enrollment in the SCN Registry** the following information is required:

1. **Blood counts and bone marrow results** indicating that you are suffering from „severe chronic neutropenia“ and additional reports classifying the neutropenia subtype will be forwarded to the SCNIR.
2. In your case we additionally need the **signed consent** for your participation from your parents or legal guardian.

After you are registered we will send a questionnaire to your treating physician once a year to ask about your latest treatment, current height and weight and your health status during the past year. In addition, we will ask for copies of your blood counts, bone marrow results and other examinations, that were performed due to your neutropenia.

Your data will be anonymized (instead of your name we will store your reports under an identification number) before entry in the SCNIR database.

We will ask exclusively for reports on examinations, that were performed because of your disease or monitoring your therapy and that would have been performed in any case independently of your participation in the registry.

Of course, all results are bound to medical confidentiality.

Participation in the SCNIR may be advantageous for you:

Although we cannot guarantee for direct benefits of participation in the SCNIR, it may be advantageous that experts in neutropenia will review your data. It may also be advantageous for you that you, your parents or your treating physician can contact the SCNIR for help and discussion of questions at any time.

If you agree to participate in the SCNIR, please sign the consent form together with your parents.