**Patient information for children**

(6 to 13 years)

Participation in the Chronic Angioedema Registry (CARE)

Dear Patient,

You are seeing your doctor because you have swellings on different parts of your body. The medical term for these swellings is "chronic or recurrent angioedema”.

We already know a lot about the causes of your swellings. However, many doctors and researchers around the world are trying to understand the swellings even better. To help us learn more about your swellings your doctor wants to ask you, if you would like to do a registry study with us.

The registry will collect your information in connection with your swellings and important information from many other patients (when did your swellings start, what caused your swellings, or how long your swellings stay before they go away). The registry also includes how much medicine helps to make the swellings not appear. So you can think of the registry as a long list with a lot of information from people who have the same or very similar swellings as you have. We use this information to learn from the different types of swellings in order to help with your treatment, and the treatment of many others who have the same problem.

The more patients help us, the more we can learn how we can help you and others better in future.

You can fill out the form with questions about your swellings together with your parents. If you need help, your parents will be able to help you to answer most of your questions. And your doctor will also discuss everything with you. You can ask us all your questions. We will be happy to answer them.

The answers you fill out will be gathered, saved in the computer and checked. If you help us, further questions will be filled into the register as well (for instance: when have new swellings taken place and what has taken place to help you). It is important that you know that your information will not be shared with anyone else than with us. You will also not have any further appointments with us.

It is your free decision if you want to help us with this registry study. If you help us, you can also change your mind at any time. There is nothing wrong with that, and you do not have to tell us why. Your decisions will not change anything for you at all. ☺