

**Netzwerk für Ichthyose und verwandte
Verhornungsstörungen (NIRK)**
Prof. Dr. H. Traupe (Sprecher)
Frau B. Willis (Netzwerkzentrale)

Universitätsklinikum Münster • Klinik und Poliklinik für Hautkrankheiten
• NIRK Zentrale • Von Esmarch-Str. 58 • 48149 Münster

Patient Label

**Klinik und Poliklinik für Hautkrankheiten
– Allgemeine Dermatologie
und Venerologie –**

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48149 Münster,

Patient information on the Network for Ichthyosis and related keratinization disorders **NIRK** and on the European network **GENESKIN**

Dear child,

We suspect that you suffer from a keratinization disorder of the skin (ichthyosis) or a related disease. In order to further define and investigate your skin disease we need from you a small amount of blood (approximately 2-30 ml) and a skin biopsy (under local anaesthesia).

Both samples will be used in the framework of investigations carried out by the network NIRK (a network formed by medical doctors and basic scientists for ichthyosis and related keratinization disorders and will also be used for scientific purposes. The samples will be studied in different centres for example Bad Salzschlirf, Berlin, Köln, Marburg, Münster, *Mainz*, Paris etc. The scientists involved and the medical doctors involved can exchange the information obtained among each other. Some samples will also be used in the framework of the European network for rare skin diseases **GENESKIN**. In some cases cell cultures will be obtained which means that cells of a biopsy will be maintained in such manner that they continue to live. The results of these investigations very often serve directly to make a proper diagnosis of your disease or will help in a long term perspective to an improvement of diagnostic and treatment options. By joining medical doctors and basic scientists in a network the diagnostic and scientific possibilities can be fully

exploited. Your data are provided in an anonymous form which means they are encrypted. Only in Münster the decryption and identification of your name will be possible.

Declaration of consent for molecular biologic analysis and for maintaining of investigational material and for participation in the study of the network for ichthyosis and related keratinization disorders NIRK and the European network for rare skin diseases GENESKIN.

- I agree that my blood and the skin biopsy which are obtained for the above mentioned diagnostic measures can also be used for scientific purposes
- I am given the guarantee that the samples taken will not be used for commercial purposes
- The obligation of the doctor on legal requirement concerning confidential medical communication will be maintained and the regulations on concerning data protection will be observed
- I am aware that my consent can be withdrawn without giving any reason and without having any negative consequences for myself

Please cross below

- () Yes, I would like to get an information of relevant results of investigations concerning myself
- () No, I do not want to know the results of these investigations as far as they concern myself

Münster, date:

Signature of the child

Signature of the parental guardian

Signature of the medical doctor