

**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 –**

Direktor: Univ.-Prof. Dr. med. Th. A. Luger

Von-Esmarch-Straße 58  
48149 Münster

Durchwahl: (02 51) 83 - 56588 (H. Traupe)  
- 57278 (B. Willis)  
- 56501 (Pforte Hautklinik)

Fax: (02 51) 83 - 57279

E-Mail: [traupeh@mednet.uni-muenster.de](mailto:traupeh@mednet.uni-muenster.de)  
[brigitte.willis@ukmuenster.de](mailto:brigitte.willis@ukmuenster.de)

[www.klinikum.uni-muenster.de](http://www.klinikum.uni-muenster.de)

[www.netzwerk-ichthyose.de](http://www.netzwerk-ichthyose.de)

Vermittlung: (02 51) 83 – 0

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

Dear patient,

We suspect that you suffer from a keratinization disorder of the skin (ichthyosis) or a related disease. To further define your skin disease we need a small amount of blood (approx. 30 ml) and a skin biopsy (under local anaesthesia) from you.

In the framework of the study of the network for ichthyosis and related keratinization disorders **NIRK** both materials will be used as well as for scientific purposes as well as for improvement of the diagnosis. In some cases we will perform cell cultures and the materials will be studied in different centres for example Bad Salzschlirf, Berlin, Köln, Marburg, *Mainz*, Münster and Paris. The scientists involved and the medical doctors involved can exchange the results among each other. By this way the diagnostic and scientific possibilities of the network can be fully exploited. Some samples will also be studied in the framework of the European network for rare skin diseases **GENESKIN**. Your data will be analyzed in an anonymous form. Only in Münster will it be possible to relate the real name for the data obtained.

**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
- The centre makes sure that the biopsies obtained will not be used for commercial purposes
- The medical obligation of the doctor on legal requirement concerning confidential medical communication will be followed and the regulations on data protection will be observed
- I am aware that my consent can be withdrawn anytime without giving any reason and without having any negative consequences for myself

Please cross below

- Yes, I would like to be informed of those investigational results that concern my directly
- No, I do not want to be informed of the investigational results which concern me directly

Münster, date:

---

Signature of the patient

---

Signature of the medical doctor