- Osteopetrosis Registry Ulm -
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D- 89075 Ulm

International Osteopetrosis Registry Ulm on behalf of the ESID and the EBMT Working Party

Informed Consent

I/We have been informed by the treating physician orally and in written form (Information Leaflet) about the Osteopetrosis Registry. I/We have had the opportunity to ask questions about the project and any questions I/we have asked have been answered to my/our satisfaction. I/We have had enough time to decide about participation in this project. I/We agree voluntarily to take part in this research project and understand that I/we have the right to withdraw from the project at any time without in any way affecting my/our child's medical care. Copies of this Consent Form and the Information Leaflet have been provided to me/us.

_____   _____
City / Date / Time   Signature of the patient

_____   _____
City / Date / Time   Signature of the mother

_____   _____
City / Date / Time   Signature of the father

INFORMATION AND CONSENT REGARDING DATA PROTECTION

In scientific studies personal data and medical information of the patient are recorded.
Data transfer, storage and analysis of this registry will be carried out respecting legal requirements and implies the following voluntary consent:

1. I/We agree that disease data of my/our child collected within the framework of this registry will be recorded on questionnaires and electronic data storage devices and will be processed without mentioning my/their name.

2. In addition I/we agree that an authorized person sworn to secrecy (e.g. of the University) will have overview of the personal data of my/our child where required to monitor the project. For this procedure I/we release the physician from the medical confidentiality.

_____   _____
City / Date / Time   Signature of the patient

_____   _____
City / Date / Time   Signature of the mother

_____   _____
City / Date / Time   Signature of the father

O   A consent for data storage in the EBMT data base (MedA/MedB) is existent (please send a copy)
O   A consent for data storage in the GPOH data base (ADAM/MARVIN) is existent (please send a copy)