

**CONSENT FORM FOR DATA REGISTRATION AFTER BONE MARROW OR
PERIPHERAL BLOOD STEM CELL TRANSPLANTATION**

For many years data on patients undergoing bone marrow or stem cell transplantation have been collected and stored in registries run by the European Group for Blood and Marrow Transplantation (EBMT). The purposes of these registries are to collect data for research and development of new and improved transplant procedures and to improve the quality of transplant procedures through the accreditation of transplant units. All data stored in the registries are non-identifiable. The data is given a UPN (Unique Personal Number) and nobody outside your treating hospital can identify you as the individual from whom the data was collected.

The European Union has issued a directive (95/46/EC) regulating collection and storage of personal data. The main purpose is to guarantee your privacy as a patient contributing data to scientific research. Important requirements of the directive are that each individual should give consent to collection and storage of personal data and where data may be sent outside of the European Union patients must expressly consent to the export of the data.

The main EBMT database is held in the Netherlands, but data may be sent outside of the EU in the following circumstances: to EBMT databases located outside of the EU (e.g. the EBMT Solid Tumour Registry in Turkey); for EBMT studies conducted in a non-European country or where data is shared with the IBMTR (International Bone Marrow Transplant Registry) in the USA.

In order to meet the regulations we ask for your consent to the collection of data concerning your transplant and to the reporting of these data to the EBMT registries

I (Patient, Parent, Guardian) have been informed to my satisfaction regarding data collection and reporting to the EBMT and

- consent to non-identifiable data on my transplant being reported to registries run by the EBMT.
- consent to non-identifiable data being sent to registries situated outside the European Union and to their use in EBMT studies conducted outside of the European Union provided the same level of protection for my privacy is applied.

Signed

Date

(Witness)

I confirm that I have explained the procedure of bone marrow / peripheral blood stem cell transplantation and the process regarding collection and storage of data to this patient who appears to have fully understood them.

Signed

Date