This is a suggested template. Each centre should adapt it to its own needs. No centre is exempted from obtaining patient consent before submitting data to the EBMT.

CONSENT FORM FOR DATA REGISTRATION WITH THE EBMT

For many years data on patients undergoing bone marrow or stem cell transplantation for any disease, and on patients undergoing immunosuppressive treatment for bone marrow failures, have been collected and stored in the Registry run by the European Group for Blood and Marrow Transplantation (EBMT). In recent years, this has been expanded with the collection of data on patients receiving non haematopoietic cell therapy.

The purpose of this registry is to collect data for research and development of new and improved transplant, cell therapy and immunosuppression procedures and to improve the quality of these procedures through the accreditation of treatment units. All data stored in the registry are non-identifiable. Each patient's report is given a database UIC (Unique Identity Code) 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 as part of international collaborations with scientific or clinical institutions (for example, sharing of data with the CIBMTR in the USA).

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

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 treatment being reported to registry run by the EBMT.

- - consent to non-identifiable data being sent to scientific or clinical institutions 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 treatment procedure and the process regarding collection and storage of data to this patient who appears to have fully understood them.
Signed ……
Date ……..