



SCETIDE Registry
Stem CELL Transplant for
ImmunoDeficiencies in Europe

Permission to share data between the EBMT and SCETIDE

10 November 2011

Chairman EBMT-IEWP &
ESID BMT-Gene therapy WP
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Dear Colleague,

SCETIDE is an international registry which works in collaboration with EBMT and ESID. It collects outcome data on transplants performed in primary immune deficiencies in Europe and runs retrospective studies in order to improve our knowledge on primary immune deficiencies.

Coordinator
Prof. Alain FISCHER
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Until now, your centre has sent data directly to SCETIDE, on request from us every 3 years. In order to facilitate the work of your centre and avoid double reporting, the EBMT has created a virtual registry for SCETIDE which will allow us to see the data needed for our processes, either new registrations or updates of previously registered stem cell transplants.

Executive Officer
Dr. Nizar MAHLAOU
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nizar.mahlaoui@nck.aphp.fr

This means that, should you agree, your centre will be able to report to EBMT and SCETIDE while submitting the data only once. In order for the data sharing to take place, it is necessary that you provide the EBMT with a formal consent allowing us to see the data from your centre which is registered in the EBMT database. This you can do by completing and returning the accompanying "Permission request form", attached to this letter, ticking the box for "Yes".

Methodologist
Prof. Paul LANDAIS
Tel # +33(0)1 44 49 46 14
Fax # +33(0)1 44 49 46 10
paul.landais@parisdescartes.fr

SCETIDE requirements are slightly different to those of the EBMT in that all transplants should be reported once 6 months have elapsed from the date of transplant but all data required is included in the EBMT Med-B forms called Inherited Disorders, using the "Primary immune deficiencies" or "Familial Lymphohystiocytosis" classifications.

Data Manager
Virginie COURTEILLE
Tel # +33(0) 1 44 49 46 23
Fax # +33(0) 1 44 49 46 25
virginie.courteille@nck.aphp.fr

In the case that you do not want to provide permission, please return the accompanying "Permission request form", ticking the box for "No".

SCETIDE Office
CEREDIH (French National Reference
Center for Primary Immune Deficiencies)
Hôpital NECKER
149, rue de Sèvres
75743 PARIS Cedex 15
www.ceredih.fr

We will be happy to answer any questions you may have regarding this request.
Thanking you for your consideration.
Yours sincerely

Pr Alain Fischer
Coordinator

Dr Nizar Mahlaoui
Executive Officer

Pr Bobby Gaspar
Chairman



Permission form for the EBMT to allow centre data to be seen by SCETIDE (Stem Cell Transplant for ImmunoDeficiencies in Europe)

I give my permission to the EBMT to share MED-AB data of our centre with study group: SCETIDE

Data to be shared:

- Any data as requested by the above society or entity
- Only items listed in the attached document

Period of sharing:

- Until further notice
- Until: Specify date

EBMT CIC code: _ _ _

Name of the Principal Investigator _____

(please print)

Position _____

Signature _____

Date _____

This form must be signed by the Principal Investigator of the centre as s/he appears in the EBMT Membership List. If the Principal Investigator has changed, please ensure it has been updated in the EBMT membership list before submitting this form.

If the centre is not an EBMT member, the form must be signed by the head of the Transplant Unit.

IMPORTANT NOTE: It is the responsibility of the centre to ensure that the permission conforms to the consent signed by the patient regarding data transmission.

Please print and return this form to:

by fax to: +44 20 7188 8411

by mail to: EBMT Central Registry Office
4th Floor, Tabard House
Guy's Hospital
Great Maze Pond
LONDON SE1 9RT
UK