

# EBMT FORM GENERAL INFORMATION

## TEAM

EBMT Centre Identification Code (CIC) .....

Hospital ..... Unit .....

Contact person: .....

Telephone ..... Fax .....

e-mail .....

Date of this report .....  
yyyy mm dd

UBMID (only if data is to be sent to CIBMTR): .....

### STUDY / TRIAL

Patient following national / international study / trial:  No  Yes  Unknown

Name of study / trial .....

## PATIENT

Unique Identification Code (UIC) ..... (to be entered only if patient previously reported)

Hospital Unique Patient Number .....

**Registrations will not be accepted if this item is left blank**

Initials ..... (first name(s) – surname(s))

Date of birth ..... Sex:  Male  Female  
yyyy mm dd

ABO Group ..... Rh factor:  Absent  Present  Not evaluated

## DISEASE

Date of diagnosis : .....  
yyyy mm dd

### PRIMARY DISEASE DIAGNOSIS (CHECK THE DISEASE FOR WHICH THIS TRANSPLANT WAS PERFORMED)

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Acute Leukaemia<br><input type="checkbox"/> Myelogenous (AML)<br><input type="checkbox"/> Lymphoblastic (ALL)<br><input type="checkbox"/> Secondary Acute Leukaemia<br><i>(do not use if transformed from MDS/MPS)</i><br><input type="checkbox"/> Chronic Leukaemia<br><input type="checkbox"/> Chronic Myeloid Leukaemia (CML)<br><input type="checkbox"/> Chronic Lymphocytic Leukaemia<br><input type="checkbox"/> Lymphoma<br><input type="checkbox"/> Non Hodgkin<br><input type="checkbox"/> Hodgkin's Disease<br><input type="checkbox"/> Other diagnosis, specify: _____ | <input type="checkbox"/> Myeloma /Plasma cell disorder<br><input type="checkbox"/> Solid Tumour<br><input type="checkbox"/> Myelodyspl. / myeloprolifer. syndrome<br><input type="checkbox"/> MDS<br><input type="checkbox"/> MPS<br><input type="checkbox"/> MD/MPS<br><input type="checkbox"/> Aplastic anaemia<br><input type="checkbox"/> Inherited disorders<br><input type="checkbox"/> Primary immune deficiencies<br><input type="checkbox"/> Metabolic disorders | <input type="checkbox"/> Histiocytic disorders<br><input type="checkbox"/> Autoimmune disease<br><input type="checkbox"/> Juvenile Idiopathic Arthritis<br><input type="checkbox"/> Multiple Sclerosis<br><input type="checkbox"/> Rheumatoid Arthritis<br><input type="checkbox"/> Systemic Lupus<br><input type="checkbox"/> Systemic Sclerosis<br><input type="checkbox"/> Haemoglobinopathy |
|--|---|---|

SPECIFICATIONS OF  
THE DISEASE**MULTIPLE SCLEROSIS**

Neurologist Name \_\_\_\_\_

Address \_\_\_\_\_

Fax \_\_\_\_\_ Email \_\_\_\_\_

**INITIAL DIAGNOSIS**

Has the information requested in this section been submitted with a previous HSCT registration?

- Yes: proceed to "Date of HSCT" on page 4  No: proceed with this section

**DIAGNOSTIC CRITERIA**

Did the patient meet the Poser criteria for clinically-definite Multiple Sclerosis?

*(Two attacks and clinical evidence of two separate lesions OR Two attacks; clinical evidence of one lesion and paraclinical evidence of another, separate lesion)*

- No  Yes  Unknown

Did the patient meet the criteria for laboratory-supported Multiple Sclerosis?

- No  Yes  Unknown

**FIRST LINE THERAPIES****THERAPIES** No – Proceed to "Date of HSCT" on page 4 Yes:Date started .....  
yyyy mm dd**Drugs:**

- No  Yes  Unknown

If yes, mark appropriate box:

- Cyclophosphamide  
 Mitoxantrone  
 Anti-lymphocyte antibodies/globulins (ALG)  
 Corticosteroids  
 Chronic low dose  
 Pulse high dose  
 Azathioprine  
 Cop-I  
  $\alpha$ -interferon  
  $\beta$ -interferon

**Irradiation (radiotherapy):**

Site

Total lymph node (TLI)  No  Yes  UnknownCraniospinal  No  Yes  Unknown

**Other modality:**

- Lymphocytophoresis  No  Yes  Unknown  
 Plasmapheresis  No  Yes  Unknown  
 Other, specify:.....

**DATE OF HSCT**

**DATE OF HSCT :** ..... - ..... - .....  
yyyy mm dd

**TRANSPLANT TYPE**

- Allogeneic: *Proceed to STATUS OF DISEASE AT HSCT on page 5*  
 Autologous: Mobilised  No: *Proceed to STATUS OF DISEASE AT HSCT on page 5*  
 Yes: Date of 1<sup>st</sup> pheresis/collection: ..... - ..... - .....  
yyyy mm dd

**STATUS OF DISEASE AT MOBILISATION**

*Evaluation should be performed less than 4 weeks prior to mobilisation for stem cell collection.*

**CLINICAL EVALUATION**

**Scripps neurological rating scale**

Score: .....  Unknown  Not evaluated

**Kurtze functional systems**

Overall score: .....  Unknown  Not evaluated

**Kurtze Expanded Disability Status**

Scale (EDSS): .....  Unknown  Not evaluated

**Composite Scale**

Score: .....  Unknown  Not evaluated

**MRI BRAIN SCAN DONE**

- Not done prior to mobilisation  
 Yes: Date of most recent MRI scan of brain: ..... - ..... - .....  Date unknown  
yyyy mm dd

**Results**

Gadolinium-enhancing lesions present  Number.....  None  Not evaluated  Unknown

## STATUS OF DISEASE AT HSCT

*Evaluation should be performed less than 2 weeks prior to conditioning*

### DISEASE COURSE

Indicate the disease course between diagnosis and mobilisation/HSCT

- Progressive relapsing (malignant)  
 Primary progressive  
 Secondary progressive (may have had previous Relapsing/Remitting)  
 Relapsing/Remitting  
 Not evaluable, explain: \_\_\_\_\_

Did the patient progress during the 2-years prior to mobilisation/HSCT?

- No       Yes, number of relapses/progressions.....       Unknown

### CLINICAL EVALUATION

#### Scripps neurological rating scale

Score: .....  Unknown     Not evaluated

#### Kurtze functional systems

Overall score: .....  Unknown     Not evaluated

#### Kurtze Expanded Disability Status

Scale (EDSS): .....  Unknown     Not evaluated

#### Composite Scale

Score: .....  Unknown     Not evaluated

### MRI BRAIN SCAN DONE

- Not done prior to HSCT  
 Yes: Date of most recent MRI scan of brain: ..... - ..... - .....       Date unknown  
yyyy    mm    dd

#### Results

Gadolinium-enhancing lesions present     Number.....     None     Unknown

## ADDITIONAL TREATMENT POST-HSCT

### ADDITIONAL TREATMENT FOR MULTIPLE SCLEROSIS

Did patient receive additional treatment post-HSCT?

No – Proceed to the ALLOGRAFT / AUTOGRAFT INSERT

Yes:

**Date started** .....  
yyyy mm dd

**Overall main reason**  Relapse/progression  
(tick only one)  Continued from pre-HSCT  
 unknown

Planned per protocol  
 Other, specify .....

### Drugs

No  Yes  Unknown

If yes, mark appropriate box:

- Cyclophosphamide
- Mitoxantrone
- Anti-lymphocyte antibodies
- Corticosteroids  
 Chronic low dose  
 Pulse high dose
- Azathioprine
- Cop-I
- $\alpha$ -interferon
- $\beta$ -interferon

### Irradiation (radiotherapy):

Site

Total lymph node (TLI)  No  Yes  Unknown

Craniospinal  No  Yes  Unknown

### Other modality:

Lymphocytapheresis  No  Yes  Unknown

Plasmapheresis  No  Yes  Unknown

Other, specify:.....

## STATUS AT 100 DAYS POST-HSCT

**DATE OF EVALUATION** ..... - ..... - .....  
yyyy mm dd

**CLINICAL EVALUATION**

**Scripps neurological rating scale**

Score: .....  Unknown  Not evaluated

**Kurtze functional systems**

Overall score: .....  Unknown  Not evaluated

**Kurtze Expanded Disability Status**

Scale (EDSS): .....  Unknown  Not evaluated

**Composite Scale**

Score: .....  Unknown  Not evaluated

**MRI BRAIN SCAN DONE**

Not done within 100 days from HSCT

Yes: Date of most recent MRI scan of brain: ..... - ..... - .....  Date unknown  
yyyy mm dd

**Results**

Are new lesions present on the MRI?

No

Yes, Indicate new lesions present:  Gadolinium-enhancing  
(check only one)  Unenhancing

Both

Unknown

Unknown

## FORMS TO BE FILLED IN

AUTOgraft, proceed to Autograft form

ALLOgraft or Syngeneic graft, proceed to Allograft form

If Cord Blood, fill in the section in Forms Appendix

If Other : ..... , contact the EBMT Central Registry Office for instructions

## FOLLOW UP

## MULTIPLE SCLEROSIS

Unique Identification Code (UIC) ..... (if known)

Date of this report .....  
yyyy mm ddPatient following national / international study / trial:  No  Yes  Unknown

Name of study / trial .....

Hospital Unique Patient Number .....

Initials: ..... (first name(s)\_surname(s))

Date of birth .....  
yyyy mm ddDate of last HSCT for this patient: .....  
yyyy mm dd

## PATIENT LAST SEEN

DATE OF LAST CONTACT OR DEATH: .....  
yyyy mm dd

## COMPLICATIONS SINCE LAST REPORT

*PLEASE USE THE DOCUMENT "DEFINITIONS OF INFECTIOUS DISEASES AND COMPLICATIONS AFTER HSCT" TO FILL THESE ITEMS. THE DOCUMENT IS AVAILABLE FROM [www.ebmt.org](http://www.ebmt.org), INFECTIOUS DISEASES WORKING PARTY.*

## INFECTION RELATED COMPLICATIONS

- No complications  
 Yes

Type	Pathogen <i>Use the list of pathogens listed after this table for guidance. Use "unknown" if necessary.</i>	Date <i>Provide different dates for different episodes of the same complication if applicable.</i>
Bacteremia / fungemia / viremia / parasites		
<b>SYSTEMIC SYMPTOMS OF INFECTION</b>		
Septic shock		
ARDS		

CIC:

Unique Patient Number (UPN): .....

SCT Date.....

yyyy mm dd

<b>Type</b>	<b>Pathogen</b> <i>Use the list of pathogens listed after this table for guidance. Use "unknown" if necessary.</i>	<b>Date</b> <i>Provide different dates for different episodes of the same complication if applicable.</i>
Multiorgan failure due to infection		
<b>ENDORGAN DISEASES</b>		
Pneumonia		
Hepatitis		
CNS infection		
Gut infection		
Skin infection		
Cystitis		
Retinitis		
Other: .....	VOTINCOM	
		yyyy mm dd

**DOCUMENTED PATHOGENS** (Use this table for guidance on the pathogens of interest)

Type	Pathogen	Type	Pathogen
Bacteria	S. pneumoniae	Viruses	HSV
	Other gram positive (i.e.: other streptococci, staphylococci, listeria ...)		VZV
	Haemophilus influenzae		EBV
	Other gram negative (i.e.: E. coli klebsiella, proteus, serratia, pseudomonas ...)		CMV
	Legionella sp		HHV-6
	Mycobacteria sp		RSV
	Other: .....		Other respiratory virus (influenza, parainfluenza, rhinovirus)
Fungi	Candida sp		Adenovirus
	Aspergillus sp		HBV
	Pneumocystis carinii		HCV
	Other: .....		HIV
			Papovavirus
Parasites	Toxoplasma gondii		Parvovirus
	Other: .....		Other: .....

**NON INFECTION RELATED COMPLICATIONS**

- No complications  
 Yes

Type (Check all that are applicable for this period)	Yes	No	Unknown	Date
Idiopathic pneumonia syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
VOD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
EBV lymphoproliferative disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Cataract	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Haemorrhagic cystitis, non infectious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
ARDS, non infectious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Multiorgan failure, non infectious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Transplant-associated microangiopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Renal failure requiring dialysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Haemolytic anaemia due to blood group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Aseptic bone necrosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other: .....	<input type="checkbox"/>			

yyyy mm dd

**GRAFT ASSESSMENT AND HAEMOPOIETIC CHIMAERISM**

**GRAFT LOSS (EQUIVALENT TO APLASIA IF AUTO)**

- No: If allo: Date graft assessed .....  
yyyy mm dd
- Chimaerism:  Full  Mixed: % donor cells .....
- Method used for chimaerism:  FISH  Molecular  
(check all that apply)  Cytogenetic  ABO Group
- Yes: Date graft loss .....  
yyyy mm dd
- If allo:  Aplasia  Autologous reconstitution
- Not evaluated

**CHRONIC GRAFT VERSUS HOST DISEASE (cGVHD)**

(allografts only)

**Presence of cGVHD**

- No (never)
- Yes:  First episode  
 Recurrence
- Date of onset of this episode: .....  
yyyy mm dd
- Present continuously since last reported episode
- cGVHD grade  Limited  Extensive
- Organs affected  Skin  Gut  Liver  Mouth  
 Eyes  Other, specify .....  Unknown
- Resolved: Date of resolution: .....  
yyyy mm dd

**SECONDARY MALIGNANCY, LYMPHOPROLIFERATIVE OR MYELOPROLIFRATIVE DISORDER DIAGNOSED**

- Previously reported
- Yes, date of diagnosis: .....  
yyyy mm dd
- Diagnosis:  AML  MDS  EBV lymphoproliferative disorder  Other .....
- No at date of this follow-up



**DISEASE TREATMENT** (apart from donor cell infusion or other type of cell therapy)

- No Proceed to 'First Evidence of Disease Worsening Since Last HSCT' on page 14
- Yes:  Planned (planned before HSCT took place)  
 Not planned (for relapse/progression or persistent disease)

**Date started** ..... - ..... - .....  
yyyy mm dd

- Overall main reason** (tick only one)
- Relapse/progression
  - Continued from pre-HSCT
  - unknown
  - Planned per protocol
  - Other, specify .....

**Drugs**

- No
- Yes
- Unknown

If yes, mark appropriate box:

- Cyclophosphamide
- Mitoxantrone
- Anti-lymphocyte antibodies
- Corticosteroids
  - Chronic low dose
  - Pulse high dose
- Azathioprine
- Cop-I
- $\alpha$ -interferon
- $\beta$ -interferon

**Irradiation (radiotherapy):**

Site

- Total lymph node (TLI)  No  Yes  Unknown
- Craniospinal  No  Yes  Unknown

**Other modality:**

- Lymphocytopheresis  No  Yes  Unknown
- Plasmapheresis  No  Yes  Unknown
- Other, specify:.....

## FIRST EVIDENCE OF DISEASE WORSENING SINCE LAST HSCT

### EVIDENCE OF DISEASE ACTIVITY

- Previously reported
- No
- Yes; date first noted: ..... - ..... - .....  
yyyy mm dd
- Continuous worsening since HSCT

Number of relapses/progressions since last HSCT.....  Unknown

## LAST DISEASE AND PATIENT STATUS

*Only if evaluation has been performed <2 weeks prior to this follow up including death*

### LAST CLINICAL EVALUATION

#### Scripps neurological rating scale

Score: .....  Unknown  Not evaluated

#### Kurtze functional systems

Overall score: .....  Unknown  Not evaluated

#### Kurtze Expanded Disability Status

Scale (EDSS): ..... - .....  Unknown  Not evaluated

#### Composite Scale

Score: ..... - .....  Unknown  Not evaluated

### MRI BRAIN SCAN DONE

- Not done
- Yes: Date of most recent MRI scan of brain: ..... - ..... - .....  Date unknown  
yyyy mm dd

#### Results

Are new lesions present on the MRI?

- No
- Yes, Indicate new lesions present:  Gadolinium-enhancing  
(check only one)  Unenhancing
- Both
- Unknown
- Unknown

### CONCEPTION

Has patient or partner become pregnant after this HSCT?

- Yes
- No
- Unknown

**SURVIVAL STATUS**

- Alive
- Dead

**PERFORMANCE SCORE** (if alive)

**Type of score used**

- Karnofsky
- Lansky

**SCORE**

- 100 (Normal, NED)
- 90 (Normal activity)
- 80 (Normal with effort)
- 70 (Cares for self)
- 60 (Requires occasional assistance)
- 50 (Requires assistance)
- 40 (Disabled)
- 30 (Severely disabled)
- 20 (Very sick)
- 10 (Moribund)
- Not evaluated
- Unknown

**CAUSE OF DEATH** (if dead)

- Relapse or progression
- Secondary malignancy
- HSCT related cause :

(check as many as appropriate)

	Yes	No	Unknown
GvHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interstitial pneumonitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pulmonary toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Infection:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> bacterial <input type="checkbox"/> viral <input type="checkbox"/> fungal <input type="checkbox"/> parasitic <input type="checkbox"/> unknown			
Rejection / poor graft function	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Veno-Occlusive disease (VOD)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Haemorrhage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cardiac toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Central nervous system toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastro intestinal toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin toxicity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Renal failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Multiple organ failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EBV lymphoproliferative disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: ..... DEACSBMR	<input type="checkbox"/>		

- Unknown

- Other : .....

**ADDITIONAL NOTES IF APPLICABLE**

**COMMENTS** .....

.....  
 .....

**IDENTIFICATION & SIGNATURE**

.....