

# 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**
**SYSTEMIC LUPUS  
ERITHEMATOSUS (SLE)**

Name of Referring Physician \_\_\_\_\_

Address \_\_\_\_\_

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

**INITIAL DIAGNOSIS**

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

 Yes: proceed to "Status of Disease at mobilisation" on page 3 No: proceed with this section
**DIAGNOSTIC CRITERIA FOR SYSTEMIC LUPUS ERYTHEMATOSUS**

Criterion	Definition	Yes	No	Not evaluated	Unkn
Malar rash [250]	Fixed erythema, flat or raised, over the malar eminences, tending to spare the nasolabial folds	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discoid rash [251]	Erythematous raised patches with adherent keratotic scaling and follicular plugging; atrophic scarring may occur in older lesions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Photosensitivity [253]	Skin rash as a result of unusual reaction to sunlight, by patient history or physician observation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oral ulcers [252]	Oral or nasopharyngeal ulceration, usually painless, observed by a physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arthritis [226]	Non-erosive arthritis involving two or more peripheral joints, characterized by tenderness, swelling or effusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Serositis [225]	a) Pleuritis – convincing history of pleuritic pain or rub heard by a physician or evidence of pleural effusion ~OR~ b) Pericarditis – documented by ECG or rub or evidence of pericardial effusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Renal disorder [213]	a) Persistent proteinuria >0.5 grams per day or >3+ on urine dipsCheck if quantitation not performed ~OR~ b) Cellular casts – may be red cell, hemoglobin, granular, tubular or mixed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologic disorder [221]	a) Seizures – in the absence of offending drugs or known metabolic derangements; e.g., uremia, ketoacidosis or electrolyte imbalance ~OR~ b) Psychosis – in the absence of offending drugs or known metabolic derangements, e.g., uremia, ketoacidosis or electrolyte imbalance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hematologic disorder [230]	a) Hemolytic anemia – with reticulocytosis ~OR~ b) Thrombocytopenia – <100,000/mm <sup>3</sup> platelets in the absence of offending drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immunologic disorder [254]	a) Anti-DNA: antibody to native DNA in abnormal titer ~OR~ b) Anti-Sm: presence of antibody to Sm nuclear antigen ~OR~ c) Positive finding of antiphospholipid antibodies based on (1) an abnormal serum level of IgG or IgM anticardiolipin antibodies, (2) a positive test result for lupus anticoagulant using a standard method, or (3) a false positive serologic test for Syphilis known to be positive for at least 6 months and confirmed by <i>Treponema pallidum</i> immobilisation or fluorescent treponemal antibody absorption test ~OR~ d) False positive serologic test for syphilis known to be positive for at least 6 months and confirmed by <i>Treponema pallidum</i> immobilisation or fluorescent treponemal antibody absorption test	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

CIC: Unique Patient Number (UPN): ..... SCT Date: .....

Criterion	Definition	SCT Date: .....			
		Yes	No	Not evaluated	Unkn
Antinuclear antibody	An abnormal titer of antinuclear antibody by immunofluorescence or an equivalent assay at any point in time and in the absence of drugs known to be associated with "drug-induced lupus" syndrome.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## FIRST LINE THERAPIES

### THERAPIES

- No – Proceed to "Date of transplant"  
 Yes:

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

#### Drugs:

*(including antibodies, GF, hormones, etc.)*

- |                                    |                          |     |                          |    |                          |         |
|------------------------------------|--------------------------|-----|--------------------------|----|--------------------------|---------|
| Androgen                           | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Anti-malarials                     | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Azathioprine                       | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Corticosteroids                    | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Cyclophosphamide                   | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Cyclosporine                       | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Mycophenolate mofetil              | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Intravenous immune globulin (IVIG) | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Other .....                        | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Lymphocytapheresis                 | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Plasmapheresis                     | <input type="checkbox"/> | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Unknown |
| Other, specify: .....              |                          |     |                          |    |                          |         |

## DATE OF HSCT

**DATE OF TRANSPLANT :** .....  
yyyy mm dd

### TRANSPLANT TYPE

- Allogeneic: Proceed to STATUS OF DISEASE AT HSCT on page 6  
 Autologous: Date of 1<sup>st</sup> collection or pheresis .....  
yyyy mm dd

## STATUS OF DISEASE AT MOBILISATION

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

### LUPUS NEPHRITIS

Was lupus nephritis present at anytime prior to mobilisation?

- Yes: Renal biopsy done?   
  Yes, date of most recent renal biopsy: .....  
yyyy mm dd  
 No  
 Unknown

Classify abnormality (*check one only*):

**Grade Histology**

- I      Normal  
 II     Mesangial  
 III    Focal proliferative  
 IV    Diffuse proliferative  
 V    Membranous  
 Other, specify \_\_\_\_\_

- No  
 Unknown

### SLEDAI (Systemic Lupus Erythematosus Disease Activity Index) score

Criterion	Definition	Yes	No	Not evaluated	Unkn	Score
Seizures [255]	Recent onset (last 10 days). Exclude metabolic, infectious or drug cause, or seizure due to past irreversible CNS damage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Psychosis [256]	Altered ability to function in normal activity due to severe disturbance in the perception of reality. Include hallucinations, incoherence, marked loose associations, impoverished thought content, marked illogical thinking, bizarre, disorganized or catatonic behavior. Exclude uremia and drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Organic brain syndrome [257]	Altered mental function with impaired orientation, memory or other intellectual function, with rapid onset and fluctuating clinical features. Include clouding of consciousness with reduced capacity to focus and inability to sustain attention to environment, plus at least 2 of the following: perceptual disturbance, incoherent speech, insomnia or daytime drowsiness or increased or decreased psychomotor activity. Exclude metabolic, infectious or drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Visual disturbance [109]	Retinal and eye changes of SLE. Include cytooid bodies, retinal hemorrhages, serous exudate or hemorrhages in the choroid, optic neuritis, scleritis or episcleritis. Exclude hypertension, infection or drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Cranial nerve disorder [258]	New onset of sensory or motor neuropathy involving cranial nerves. Include vertigo due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Lupus headache [259]	Severe, persistent headache: may be migrainous, but must be nonresponsive to narcotic analgesia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
CVA [260]	New onset of cerebrovascular accident(s). Exclude arteriosclerosis or hypertensive causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Vasculitis [234]	Ulceration, gangrene, tender finger nodules, periungual infarction, splinter hemorrhages or biopsy or angiogram proof of vasculitis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Arthritis [226]	More than 2 joints with pain and signs of inflammation (i.e., tenderness, swelling or effusion).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4

Criterion	Definition	yyyy mm dd Yes No Not Unkn evaluated				Score
		Myositis [261]	Proximal muscle aching/weakness, associated with elevated creatine phosphokinase/aldolase or electromyogram changes or a biopsy showing myositis.	<input type="checkbox"/>	<input type="checkbox"/>	
Urinary casts [262]	Heme-granular or red blood cell casts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Hematuria [263]	>5 red blood cells/high power field. Exclude stone, infection or other cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Proteinuria [264]	>0.5 gm/24 hours. New onset or recent increase of >0.5 gm/24 hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Pyuria [265]	>5 white blood cells/high power field. Exclude infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
New rash [249]	Ongoing inflammatory lupus rash.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Alopecia [266]	Ongoing abnormal, patchy or diffuse loss of hair due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Mucosal ulcers [252]	Ongoing oral or nasal ulcerations due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pleurisy [267]	Classic and severe pleuritic chest pain or pleural rub or effusion or new pleural thickening due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pericarditis [268]	Classic and severe pericardial pain or rub or effusion or electrocardiogram confirmation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Low complement [269]	Decrease in CH50, C3 or C4 below the lower limit of normal for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Increased DNA binding [270]	>25% binding by Farr assay or above normal range for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Fever [271]	>38°C. Exclude infectious cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Thrombocytopenia [272]	<100,000 platelets/mm <sup>3</sup> (x 10 <sup>9</sup> /L).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Leukopenia [272]	<3,000 white blood cells/mm <sup>3</sup> (x 10 <sup>9</sup> /L). Exclude drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
<b>TOTAL SLEDAI SCORE =</b>						

**LABORATORY VALUES**

Haemoglobin	..... - ..... g/dL		<b>Units</b>	<b>Not evaluated</b>	<b>Unknown</b>
Erythrocyte sedimentation rate	..... mm/hr	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Platelets	..... 10 <sup>9</sup> /l	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
WBC	..... - ..... 10 <sup>9</sup> /l	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Serum creatinine	..... - ..... µmol/l	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Creatinine clearance	..... - ..... ml/min	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Total urinary protein excretion	..... - ..... mg/24hr	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
		<b>No</b>	<b>Yes</b>	<b>Not evaluated</b>	<b>Unknown</b>
CH50 Complement reduced		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C3 reduced		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C4 reduced		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Antibodies studied**                       No                       Yes                       Unknown

If yes:

anti-dsDNA	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-cardiolipin IgG	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-cardiolipin IgM	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
antinuclear antibody (ANA) test	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-Sm	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-SSA (anti-Ro)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-SSB (anti-La)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
lupus-anticoagulant	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown

**PATIENT’S SELF ASSESSMENT PRIOR TO MOBILISATION**

**HEALTH SURVEY**

SF-36™ Health Survey completed                       No                       Yes                       Unknown

If yes, score reported as:  Transformed Score     Raw score     Unknown  
*(range 0-100)*

Partial score:    Physical Functioning:                      ..... - .....     Not evaluated     Unknown

                          Role Functioning-Physical:                      ..... - .....     Not evaluated     Unknown

                          Role Functioning-Emotional:                      ..... - .....     Not evaluated     Unknown

                          Social Functioning:                      ..... - .....     Not evaluated     Unknown

                          Bodily Pain:                      ..... - .....     Not evaluated     Unknown

                          Mental Health:                      ..... - .....     Not evaluated     Unknown

                          Vitality:                      ..... - .....     Not evaluated     Unknown

                          General Health:                      ..... - .....     Not evaluated     Unknown

**HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)**

	<b>No</b>	<b>Yes</b>	<b>Unknown</b>
Did the patient complete a Health Assessment Questionnaire (HAQ)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient's score:	..... - .....		
Worst possible score:	..... - .....		
Best possible score:	..... - .....		



Criterion	Definition	evaluated				Score
		Yes	No	Not	Unkn	
Hematuria [263]	>5 red blood cells/high power field. Exclude stone, infection or other cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Proteinuria [264]	>0.5 gm/24 hours. New onset or recent increase of >0.5 gm/24 hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Pyuria [265]	>5 white blood cells/high power field. Exclude infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
New rash [249]	Ongoing inflammatory lupus rash.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Alopecia [266]	Ongoing abnormal, patchy or diffuse loss of hair due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Mucosal ulcers [252]	Ongoing oral or nasal ulcerations due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pleurisy [267]	Classic and severe pleuritic chest pain or pleural rub or effusion or new pleural thickening due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pericarditis [268]	Classic and severe pericardial pain or rub or effusion or electrocardiogram confirmation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Low complement [269]	Decrease in CH50, C3 or C4 below the lower limit of normal for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Increased DNA binding [270]	>25% binding by Farr assay or above normal range for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Fever [271]	>38°C. Exclude infectious cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Thrombocytopenia [272]	<100,000 platelets/mm <sup>3</sup> (x 10 <sup>9</sup> /L).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Leukopenia [272]	<3,000 white blood cells/mm <sup>3</sup> (x 10 <sup>9</sup> /L). Exclude drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
<b>TOTAL SLEDAI SCORE =</b>						

**LABORATORY VALUES**

	Units	Not evaluated	Unknown
Haemoglobin	..... g/dL	<input type="checkbox"/>	<input type="checkbox"/>
Platelets	..... 10 <sup>9</sup> /l	<input type="checkbox"/>	<input type="checkbox"/>
WBC	..... 10 <sup>9</sup> /l	<input type="checkbox"/>	<input type="checkbox"/>
Erythrocyte sedimentation rate	..... mm/hr	<input type="checkbox"/>	<input type="checkbox"/>
Serum creatinine	..... µmol/l	<input type="checkbox"/>	<input type="checkbox"/>
Creatinine clearance	..... ml/min	<input type="checkbox"/>	<input type="checkbox"/>
Total urinary protein excretion	..... mg/24hr	<input type="checkbox"/>	<input type="checkbox"/>

	No	Yes	Not evaluated	Unknown
CH50 Complement reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C3 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C4 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Antibodies studied**

No       Yes       Unknown

If yes:

anti-dsDNA	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-cardiolipin IgG	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-cardiolipin IgM	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
antinuclear antibody (ANA) test	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-Sm	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-SSA (anti-Ro)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
anti-SSB (anti-La)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
lupus-anticoagulant	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown

**PATIENT'S SELF ASSESSMENT PRIOR TO CONDITIONING**

**HEALTH SURVEY**

SF-36™ Health Survey completed  No  Yes  Unknown

If yes, score reported as:  Transformed Score  Raw score  Unknown  
*(range 0-100)*

Partial score: Physical Functioning: ..... - .....  Not evaluated  Unknown  
 Role Functioning-Physical: ..... - .....  Not evaluated  Unknown  
 Role Functioning-Emotional: ..... - .....  Not evaluated  Unknown  
 Social Functioning: ..... - .....  Not evaluated  Unknown  
 Bodily Pain: ..... - .....  Not evaluated  Unknown  
 Mental Health: ..... - .....  Not evaluated  Unknown  
 Vitality: ..... - .....  Not evaluated  Unknown  
 General Health: ..... - .....  Not evaluated  Unknown

**HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)**

**No Yes Unknown**

Did the patient complete a Health Assessment Questionnaire (HAQ)?

Patient's score: ..... - .....  
 Worst possible score: ..... - .....  
 Best possible score: ..... - .....

**ADDITIONAL TREATMENT POST-HSCT**

**ADDITIONAL DISEASE TREATMENT**

- No
- Yes:  Planned *(planned before HSCT took place)*
- Not planned *(for relapse/progression or persistent disease)*

## FOLLOW UP

# SYSTEMIC LUPUS ERITHEMATOSUS (SLE)

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

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

Patient 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 dd

Date 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		
		<i>yyyy mm dd</i>

**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

CIC: Unique Patient Number (UPN): ..... SCT Date: .....  
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

**ADDITIONAL THERAPIES SINCE LAST FOLLOW UP**

**Treatment given since last report**

- No
- Yes: Date started: .....  
yyyy mm dd
- Unknown



## 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

## LAST DISEASE AND PATIENT STATUS

**SLEDAI (SYSTEMIC LUPUS ERYTHEMATOSUS DISEASE ACTIVITY INDEX) SCORE**

Criterion	Definition	Yes	No	Not evaluated	Unkn	Score
Seizures [255]	Recent onset (last 10 days). Exclude metabolic, infectious or drug cause, or seizure due to past irreversible CNS damage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Psychosis [256]	Altered ability to function in normal activity due to severe disturbance in the perception of reality. Include hallucinations, incoherence, marked loose associations, impoverished thought content, marked illogical thinking, bizarre, disorganized or catatonic behavior. Exclude uremia and drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Organic brain syndrome [257]	Altered mental function with impaired orientation, memory or other intellectual function, with rapid onset and fluctuating clinical features. Include clouding of consciousness with reduced capacity to focus and inability to sustain attention to environment, plus at least 2 of the following: perceptual disturbance, incoherent speech, insomnia or daytime drowsiness or increased or decreased psychomotor activity. Exclude metabolic, infectious or drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Visual disturbance [109]	Retinal and eye changes of SLE. Include cytoid bodies, retinal hemorrhages, serous exudate or hemorrhages in the choroid, optic neuritis, scleritis or episcleritis. Exclude hypertension, infection or drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Cranial nerve disorder [258]	New onset of sensory or motor neuropathy involving cranial nerves. Include vertigo due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Lupus headache [259]	Severe, persistent headache: may be migrainous, but must be nonresponsive to narcotic analgesia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
CVA [260]	New onset of cerebrovascular accident(s). Exclude arteriosclerosis or hypertensive causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Vasculitis [234]	Ulceration, gangrene, tender finger nodules, periungual infarction, splinter hemorrhages or biopsy or angiogram proof of vasculitis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
Arthritis [226]	More than 2 joints with pain and signs of inflammation (i.e., tenderness, swelling or effusion).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Myositis [261]	Proximal muscle aching/weakness, associated with elevated creatine phosphokinase/aldolase or electromyogram changes or a biopsy showing myositis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Urinary casts [262]	Heme-granular or red blood cell casts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Hematuria [263]	>5 red blood cells/high power field. Exclude stone, infection or other cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Proteinuria [264]	>0.5 gm/24 hours. New onset or recent increase of >0.5 gm/24 hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Pyuria [265]	>5 white blood cells/high power field. Exclude infection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
New rash [249]	Ongoing inflammatory lupus rash.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Alopecia [266]	Ongoing abnormal, patchy or diffuse loss of hair due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2

Criterion	Definition	evaluated				Score
		Yes	No	Not	Unkn	
Mucosal ulcers [252]	Ongoing oral or nasal ulcerations due to active lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pleurisy [267]	Classic and severe pleuritic chest pain or pleural rub or effusion or new pleural thickening due to lupus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Pericarditis [268]	Classic and severe pericardial pain or rub or effusion or electrocardiogram confirmation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Low complement [269]	Decrease in CH50, C3 or C4 below the lower limit of normal for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Increased DNA binding [270]	>25% binding by Farr assay or above normal range for testing laboratory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Fever [271]	>38°C. Exclude infectious cause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Thrombocytopenia [272]	<100,000 platelets/mm <sup>3</sup> (x 10 <sup>9</sup> /L).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Leukopenia [272]	<3,000 white blood cells/mm <sup>3</sup> (x 10 <sup>9</sup> /L). Exclude drug causes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
<b>TOTAL SLEDAI SCORE =</b>						

**LABORATORY VALUES**

	Units	Not evaluated	Unknown
Haemoglobin	..... - ..... g/dL	<input type="checkbox"/>	<input type="checkbox"/>
Platelets	..... 10 <sup>9</sup> /l	<input type="checkbox"/>	<input type="checkbox"/>
WBC	..... - ..... 10 <sup>9</sup> /l	<input type="checkbox"/>	<input type="checkbox"/>
Erythrocyte sedimentation rate	..... mm/hr	<input type="checkbox"/>	<input type="checkbox"/>
Serum creatinine	..... - ..... µmol/l	<input type="checkbox"/>	<input type="checkbox"/>
Creatinine clearance	..... - ..... ml/min	<input type="checkbox"/>	<input type="checkbox"/>
Total urinary protein excretion	..... - ..... mg/24hr	<input type="checkbox"/>	<input type="checkbox"/>

	No	Yes	Not evaluated	Unknown
CH50 Complement reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C3 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complement component C4 reduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Antibodies studied**

	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Unknown
If yes:			
anti-dsDNA	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-cardiolipin IgG	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-cardiolipin IgM	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
antinuclear antibody (ANA) test	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-Sm	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-SSA (anti-Ro)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
anti-SSB (anti-La)	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
lupus-anticoagulant	<input type="checkbox"/> Normal	<input type="checkbox"/> Elevated	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown

**PATIENT'S SELF ASSESSMENT AT THIS FOLLOW UP**

**HEALTH SURVEY**

SF-36™ Health Survey completed  No  Yes  Unknown  
 If yes, score reported as:  Transformed Score  Raw score  Unknown  
*(range 0-100)*

Partial score: Physical Functioning: ..... - .....  Not evaluated  Unknown  
 Role Functioning-Physical: ..... - .....  Not evaluated  Unknown  
 Role Functioning-Emotional: ..... - .....  Not evaluated  Unknown  
 Social Functioning: ..... - .....  Not evaluated  Unknown  
 Bodily Pain: ..... - .....  Not evaluated  Unknown  
 Mental Health: ..... - .....  Not evaluated  Unknown  
 Vitality: ..... - .....  Not evaluated  Unknown  
 General Health: ..... - .....  Not evaluated  Unknown

**HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)**

**No Yes Unknown**

Did the patient complete a Health Assessment Questionnaire (HAQ)?     
 Patient's score: ..... - .....  
 Worst possible score: ..... - .....  
 Best possible score: ..... - .....

**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)  Not evaluated  
 90 (Normal activity)  Unknown  
 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)

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yyyy mm dd

**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**