

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

SPECIFICATIONS
OF THE DISEASEJUVENILE IDIOPATHIC ARTHRITIS
(JIA)

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

SUBCLASSIFICATION AT DIAGNOSIS

- Systemic
- Polyarticular Rheumatoid Arthritis
- with oligoarticular onset
- with polyarticular onset
- Other, specify: _____

COURSE OF THE DISEASE UNTIL MOBILISATION/TRANSPLANT

(At any time between diagnosis and mobilisation/transplant)

DISEASE STATUS

- Systemic JIA with polyarticular course: No Yes Not evaluated Unknown
- Schneider criteria fulfilled? No Yes: Only at diagnosis
- persistent thrombocytosis* At diagnosis and after
- corticosteroids to control fever* Only after
- Not evaluated Unknown
- Disease progression on therapy No Yes Not evaluated Unknown
- Corticosteroid dependency to control disease No Yes Not evaluated Unknown

LABORATORY DATA

- Erythrocyte sedimentation rate mm/hr Not evaluated Unknown
- C-reactive protein Normal Elevated

AUTOANTIBODIES

- Were tests for autoantibodies done between diagnosis and mobilisation/transplant?
- No Yes Unknown

Specify antibody:

- Anti-nuclear (ANA) Negative Positive Not evaluated Unknown
- Rheumatoid factor Negative Positive Not evaluated Unknown
- Other, specify: _____ Negative Positive

FIRST LINE THERAPIES

DISEASE MODIFYING DRUGS AND IMMUNOSUPPRESSANTS

 No – Proceed to "Date of HSCT"

 Yes:

Date started
yyyy mm dd

- Yes, mark appropriate box(es)
 Cyclophosphamide
 Cyclosporin-A
 Methotrexate
 Corticosteroids
 Non-steroidal anti-inflammatory (NSAIDS)
 Anti tumour necrosis factor (*Etanercept*)
 Other drug or agent _____
 Unknown

Other treatment No Yes: _____ Unknown

COMPLICATIONS DUE TO TOXICITY FROM CONVENTIONAL TREATMENT

 No complications

 Yes:

- | | | | |
|---|-----------------------------|------------------------------|----------------------------------|
| Cataracts | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Avascular necrosis of femoral head | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Severe hypertension | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Renal insufficiency (>30% increase in creatinine) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Severe gastrointestinal (GI) toxicity, specify: _____ | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Hepatic dysfunction (≥ 3 fold increase in liver function tests) | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Severe gastrointestinal (GI) toxicity, specify: _____ | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Growth delay | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Unknown |
| Other, specify: _____ | | | |

 Unknown

Did severe myelosuppression occur? No Yes Not evaluated Unknown

DATE OF HSCT

DATE OF TRANSPLANT :
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 1st pheresis/collection:
yyyy mm dd

STATUS OF DISEASE AT MOBILISATION

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

DISEASE STATUS

Number of painful/tender joints : Not evaluated Unknown
(Eular/ACR 28 joint count, which comprises bilateral shoulders, elbows, wrists, MCPs, PIPs and knees. Appendix B.2)

Number of swollen/effused joints : Not evaluated Unknown
(Eular/ACR 28 joint count, see above)

Pediatric EPM-Range of motion final score (0-3) : Not evaluated Unknown
(Appendix B.3)

Was morning stiffness present?

Yes, specify duration: hours minutes No Not evaluated Unknown

Patient's weight: Kg Not evaluated Unknown

Patient's height: cm Not evaluated Unknown

Patient's weight **one year** prior to time of mobilisation: Kg Not evaluated Unknown

Patient's height **one year** prior to time of mobilisation: cm Not evaluated Unknown

HAEMATOLOGICAL VALUES

Haemoglobin g/dL Not evaluated Unknown

Erythrocyte sedimentation rate mm/hr Not evaluated Unknown

Platelets: ($10^9/l$) Not evaluated Unknown

WBC ($10^9/l$) Not evaluated Unknown

DIFFERENTIAL:

Segs: % Not evaluated Unknown

Bands: % Not evaluated Unknown

Lymphocytes: % Not evaluated Unknown

Basophils: % Not evaluated Unknown

Monocytes: % Not evaluated Unknown

Eosinophils: % Not evaluated Unknown

CLINICAL AND LABORATORY DATA

Serum creatinine $\mu\text{mol/l}$ Not evaluated Unknown

Serum AST (IU/l) Not evaluated Unknown

Serum ALT (IU/l) Not evaluated Unknown

Serum albumin (g/dl) Not evaluated Unknown

Serum alkaline phosphatase (IU/l) Not evaluated Unknown

Total serum bilirubin (mg/dl) Not evaluated Unknown

C-reactive protein Normal Elevated Not evaluated Unknown

AUTOANTIBODIES

Were tests for autoantibodies done between diagnosis and mobilisation/transplant?
 No Yes Unknown

Specify antibody:

Anti-nuclear (ANA) Negative Positive Not evaluated Unknown
 Rheumatoid factor Negative Positive Not evaluated Unknown
 Other, specify: _____ Negative Positive

RADIOGRAPHIC EVALUATION

Were radiographic bone erosions present? Negative Positive Not evaluated Unknown

Was advanced skeletal age of affected joints noted radiographically?
 No Yes Not evaluated Unknown

Presence of osteoporotic fractures Never Previously but not now Currently
 Not evaluated Unknown

HEALTH ASSESSMENT QUESTIONNAIRE OR SURVEY COMPLETED

No Yes unknown

PATIENT'S SELF ASSESSMENT

Done Not done Unknown

Childhood Health Assessment Questionnaire (**CHAQ**) completed?
(see Appendix B.4)

If yes: Specify range of possible scores for the **CHAQ pain** sub-scale:

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

Specify range of possible scores for the **CHAQ disability** sub-scale:

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

Specify range of possible scores for the **CHAQ severity** sub-scale:

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

PHYSICIAN'S ASSESSMENT

Done Not done Unknown

Did the physician complete a **Global** Assessment of the patient's state?

If yes: Specify range of possible scores for Physician Rated Global Assessment:

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

DISEASE RESPONSE TO THE MOBILISATION

Response Transient No response Not evaluated

STATUS OF DISEASE AT HSCT

Evaluation should be performed <2 weeks prior to conditioning

DISEASE STATUS

Number of painful/tender joints : Not evaluated Unknown
(Eular/ACR 28 joint count, which comprises bilateral shoulders, elbows, wrists, MCPs, PIPs and knees. Appendix B.2)

Number of swollen/effused joints : Not evaluated Unknown
(Eular/ACR 28 joint count, see above)

Pediatric EPM-Range of motion final score (0-3) : Not evaluated Unknown
(Appendix B.3)

Was morning stiffness present?
 Yes, specify duration: hours minutes No Not evaluated Unknown

Patient's weight **one year** prior to time of transplant: Kg Not evaluated Unknown

Patient's height **one year** prior to time of transplant: cm Not evaluated Unknown

HAEMATOLOGICAL VALUES

	Units	Not evaluated	Unknown
Haemoglobin	g/dL	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Erythrocyte sedimentation rate	mm/hr	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Platelets:	(10 ⁹ /l)	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
WBC	(10 ⁹ /l)	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
DIFFERENTIAL:			
Segs: %		<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Bands: %		<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Lymphocytes: %		<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Basophils: %		<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Monocytes: %		<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Eosinophils: %		<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown

CLINICAL AND LABORATORY DATA

Serum albumin	(g/dl)	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Serum alkaline phosphatase	(IU/l)	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
C-reactive protein <input type="checkbox"/> Normal <input type="checkbox"/> Elevated		<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown

AUTOANTIBODIES

Were tests for autoantibodies done between diagnosis and mobilisation/transplant?
 No Yes Unknown

Specify antibody:

Anti-nuclear (ANA) <input type="checkbox"/> Negative <input type="checkbox"/> Positive	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Rheumatoid factor <input type="checkbox"/> Negative <input type="checkbox"/> Positive	<input type="checkbox"/> Not evaluated	<input type="checkbox"/> Unknown
Other, specify: _____ <input type="checkbox"/> Negative <input type="checkbox"/> Positive		

RADIOGRAPHIC EVALUATION

Were radiographic bone erosions present? Negative Positive Not evaluated Unknown
Was advanced skeletal age of affected joints noted radiographically?
 No Yes Not evaluated Unknown
Presence of osteoporotic fractures Never Previously but not now Currently
 Not evaluated Unknown

HEALTH ASSESSMENT QUESTIONNAIRE OR SURVEY COMPLETED

No Yes unknown

PATIENT'S SELF ASSESSMENT

Done Not done Unknown

Childhood Health Assessment Questionnaire (CHAQ) completed?

(see Appendix B.4)

If yes: Specify range of possible scores for the **CHAQ pain** sub-scale:

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

Specify range of possible scores for the **CHAQ disability** sub-scale:

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

Specify range of possible scores for the **CHAQ severity** sub-scale:

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

PHYSICIAN'S ASSESSMENT

Done Not done Unknown

Did the physician complete a **Global** Assessment of the patient's state?

If yes: Specify range of possible scores for Physician Rated Global Assessment:

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

CLINICAL AND LABORATORY DATA

Erythrocyte sedimentation rate mm/hr
 C-reactive protein Normal Elevated

RADIOGRAPHIC EVALUATION

Were radiographic bone erosions present? Negative Positive Not evaluated Unknown
 Was advanced skeletal age of affected joints noted radiographically?
 No Yes Not evaluated Unknown
 Presence of osteoporotic fractures Never Previously but not now Currently
 Not evaluated Unknown

HEALTH ASSESSMENT QUESTIONNAIRE OR SURVEY COMPLETED

PATIENT'S SELF ASSESSMENT

Done Not done Unknown

Childhood HEALTH ASSESSMENT QUESTIONNAIRE (CHAQ) completed?
 (see Appendix B.4)

If yes: Specify range of possible scores for the CHAQ PAIN sub-scale:

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

Specify range of possible scores for the CHAQ DISABILITY sub-scale:

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

Specify range of possible scores for the CHAQ SEVERITY sub-scale:

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

PHYSICIAN'S ASSESSMENT

Done Not done Unknown

Did the physician complete a GLOBAL ASSESSMENT of the patient's state?

If yes: Specify range of possible scores for PHYSICIAN RATED GLOBAL ASSESSMENT:

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

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

JUVENILE IDIOPATHIC
ARTHRITIS (JIA)

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, 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		
SYSTEMIC SYMPTOMS OF INFECTION		
Septic shock		
ARDS		

CIC:

Unique Patient Number (UPN):

SCT Date.....

yyyy mm dd

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>
Multiorgan failure due to infection		
ENDORGAN DISEASES		
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

ADDITIONAL THERAPIES SINCE LAST FOLLOW UP

Treatment given since last report

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

If yes:

CELLULAR THERAPY

One cell therapy regimen is defined as any number of infusions given within 10 weeks for the same indication. If more than one regimen of cell therapy, according to the above definition, has been given since last report, copy this section and complete it as many times as necessary.

- No
 Yes: Disease status before this cellular therapy CR Not in CR Not evaluated
 Unknown

If yes:

Type of cells

- Donor lymphocyte infusion (DLI)
 Mesenchymal cells
 Other

 Unknown

Number of cells infused by type	
Nucleated cells (/kg*) (DLI only) - x 10 ⁸ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown
CD 34+ (cells/kg*) (DLI only) - x 10 ⁶ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown
CD 3+ (cells/kg*) (DLI only) - x 10 ⁶ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown
Total number of cells infused	
All cells (cells/kg*) (non DLI only) - x 10 ⁶ <input type="checkbox"/> Not evaluated <input type="checkbox"/> unknown

Chronological number of this cell therapy for this patient

Indication (check all that apply)

- Planned/protocol Treatment for disease
 Prophylactic Mixed chimaerism
 Treatment of GvHD Treatment viral infection
 Loss/decreased chimaerism Treatment PTLD, EBV lymphoma
 Other, specify

Number of infusions within 10 weeks

(count only infusions that are part of same regimen and given for the same indication)

Acute Graft Versus Host Disease (after this infusion but before any further infusion / HSCT):

- Maximum grade grade 0 (absent) grade 1 grade 2
 grade 3 grade 4 present, grade unknown

ADDITIONAL DISEASE MODIFYING DRUGS AND IMMUNOSUPPRESSANTS FOR JIA

- No *Proceed to FIRST EVIDENCE OF DISEASE WORSENING SINCE LAST HSCT*
- Yes: Planned (*planned before HSCT took place*)
 - Not planned (*for relapse/progression or persistent disease*)

Date started
yyyy mm dd

Drugs or agents:

- No
- Yes, mark appropriate box(es)
 - Cyclophosphamide
 - Cyclosporin-A
 - Methotrexate
 - Corticosteroids
 - Non-steroidal anti-inflammatory (NSAIDS)
 - Anti tumour necrosis factor (*Etanercept*)
 - Other drug or agent _____
- Unknown

Other treatment No Yes: _____ 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

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

DISEASE STATUS

Number of painful/tender joints : Not evaluated Unknown
(Eular/ACR 28 joint count, which comprises bilateral shoulders, elbows, wrists, MCPs, PIPs and knees. Appendix B.2)

Number of swollen/effused joints : Not evaluated Unknown
(Eular/ACR 28 joint count, see above)

Pediatric EPM-Range of motion final score (0-3) : Not evaluated Unknown
(Appendix B.3)

Was morning stiffness present?

Yes, specify duration: hours minutes No Not evaluated Unknown

Patient's weight: Kg Not evaluated Unknown

Patient's height: cm Not evaluated Unknown

CLINICAL AND LABORATORY DATA

Units

Not evaluated

Unknown

Erythrocyte sedimentation rate mm/hr

C-reactive protein Normal Elevated

RADIOGRAPHIC EVALUATION

Were radiographic bone erosions present? Negative Positive Not evaluated Unknown

Was advanced skeletal age of affected joints noted radiographically?

No Yes Not evaluated Unknown

Presence of osteoporotic fractures Never Previously but not now Currently
 Not evaluated Unknown

SURVEYS COMPLETED

No Yes unknown

PATIENT'S SELF ASSESSMENT

Done Not done Unknown

Childhood HEALTH ASSESSMENT QUESTIONNAIRE (CHAQ) completed?
(see Appendix B.4)

If yes: Specify range of possible scores for the CHAQ PAIN sub-scale:

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

Specify range of possible scores for the CHAQ DISABILITY sub-scale:

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

Specify range of possible scores for the CHAQ SEVERITY sub-scale:

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

PHYSICIAN'S ASSESSMENT

Done Not done Unknown

Did the physician complete a GLOBAL ASSESSMENT of the patient's state?

If yes: Specify range of possible scores for PHYSICIAN RATED GLOBAL ASSESSMENT:

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)

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

.....

APPENDIX B

AUTOIMMUNE DISEASES

1. Poser CM, Paty DW, Scheinber L, et al, Ann Neurol, 1983, 13:227-231
2. Fuchs and Pincus, Arthritis Rheum, 1994, 37:470
3. Len. C, et al, J Rheum, 1999, 26(4):909-913
4. Singh G, Athreya B, Fries J, Goldsmith DP. Measurement of health status in children with rheumatoid arthritis. "Arthritis Rheum" 1994, 37:1761-69)
5. Giannini EH, et al, "Arthritis Rheum" 1997, Jul; 40 (7): 1202-9)
6. Arnett et al, "Arthritis Rheum" 1988, 31:315)
7. Felson et al, "Arthritis Rheum" 1995, 38:727)
8. Pinals et al, "Arthritis Rheum" 1981, 24:1308)
9. Austin HA III, et al, Kidney Int, 1984, 25:689)
10. Clements P, et al, J Rheumatol, 1995, 22:1281-5)
11. Steen VD, Arthritis Rheum, 1997, Nov; 40 (11): 1984-91