

HSCT - Minimum Essential Data - A

First report - 100 days after HSCT

AFTER HSCT

GvHD prophylaxis given (Allografts only)

- No
- Yes: Immunosuppressive chemotherapy
- ALG, ALS, ATG, ATS (given after day 0)
 - Anti CD25 (MoAB in vivo)
 - Campath (MoAB in vivo; can be "in the bag")
 - Corticosteroids
 - Cyclosporine
 - Etanercept (MoAB in vivo)
 - FK 506 (Tacrolimus, Prograf)
 - Infliximab (MoAB in vivo)
 - Methotrexate
 - Mycophenolate (MMF)
 - Sirolimus
 - Other monoclonal antibody (in vivo), specify
 - Other agent (in vivo), specify
- Extracorporeal photopheresis (ECP)
- Other, specify

Absolute neutrophil count (ANC) recovery (engraftment)
(Neutrophils $\geq 0.5 \times 10^9/L$)

- No: Date of last assessment: - -
yyyy mm dd
- Yes: Date of ANC recovery: - -
yyyy mm dd

- Lost graft
- Never below
- Unknown

Acute Graft Versus Host Disease (Allografts only)

- Maximum Grade:
- 0 (none) I II III IV
- Present but grade unknown Not applicable

ADDITIONAL TREATMENT INCLUDING

CELL INFUSION

Cell infusion (CI) (not HSCT or autologous stem cell re-infusion)

- No Yes

Date of first infusion:
(can be the same as HSCT date) yyyy mm dd

Type of cell(s): (check all that apply)

- Lymphocyte Mesenchymal Fibroblasts
- Dendritic cells Other, specify

Chronological no. of CI 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)

Disease treatment (apart from cell infusion)

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

DISEASE STATUS

Best disease status (response) after HSCT

(prior to treatment modification in response to a post HSCT disease assessment)

- Continued complete remission (CR)
- CR achieved: Date achieved : - -
yyyy mm dd
- Never in CR: Date assessed: - -
yyyy mm dd
- Not evaluated

DATE OF LAST CONTACT

Date of last follow up or death: - -
yyyy mm dd

FIRST RELAPSE OR PROGRESSION

First Relapse or Progression after HSCT (Any type)

- No Yes Continuous progression since HSCT
- If **yes** or **continuous progression** and for acute and chronic **LEUKAEMIAS** only, tick all methods used for assessment with the dates on which they were used and the results.

Relapse/progression detected by clinical/haematological method:

- No: Date assessed - -
yyyy mm dd
- Yes: Date first seen - -
yyyy mm dd
- Not evaluated - -
yyyy mm dd

Relapse/progression detected by cytogenetic method:

- No: Date assessed - -
yyyy mm dd
- Yes: Date first seen - -
yyyy mm dd
- Not evaluated - -
yyyy mm dd

Relapse/progression detected by molecular method:

- No: Date assessed - -
yyyy mm dd
- Yes: Date first seen - -
yyyy mm dd
- Not evaluated - -
yyyy mm dd

DISEASE PRESENCE/DETECTION AT LAST CONTACT

Last disease status (record the most recent status and date for each method, depending on the disease)

Was disease detected by clinical/haematological method?:

- No Yes
- Last date assessed - -
yyyy mm dd
- Not evaluated - -
yyyy mm dd

Fill in only for acute and chronic **LEUKAEMIAS**

Was disease detected by cytogenetic/FISH method?:

- No Yes:
- Considered disease relapse/progression: No Yes
- Last date assessed - -
yyyy mm dd
- Not evaluated - -
yyyy mm dd

Fill in only for acute and chronic **LEUKAEMIAS**

Was disease detected by molecular method?:

- No Yes:
- Considered disease relapse/progression No Yes
- Last date assessed - -
yyyy mm dd
- Not evaluated - -
yyyy mm dd

PATIENT STATUS AT LAST CONTACT

Survival Status:

- Alive Dead Died before HSCT
- Check here if patient lost to follow up

Main Cause of Death (check only one main cause):

- Relapse or Progression/Persistent disease
- HSCT Related Cause
- (check as many as appropriate):
- GVHD Cardiac Toxicity
- Rejection/Poor graft function Infection
- Pulmonary toxicity Veno occlusive disorder
- Other:.....
- Unknown
- Other:

DATE OF NEXT HSCT

(if applicable)

Date of this HSCT: - -
yyyy mm dd

HISTOCOMPATIBILITY

PLEASE SEND COPIES OF THE ORIGINAL HLA TYPING FORM(S).
If you do so, you do not need to fill in this HISTOCOMPATIBILITY section

LOCATION

Laboratory / Hospital Unit

Contact number (telephone/fax)

Technique Used

DONOR HLA PHENOTYPE

IF MULTIPLE DONORS:

Donor number in the infusion order.....

Donor ID..... (or use date of birth to identify donor in this section)

A revised listing of recognised HLA specificities is issued by the WHO nomenclature and is available at:
http://hla.alleles.org/nomenclature/nomenclature_2009.html

HLA Type	A		B		C	
Antigenic (Serology)						
Allelic (DNA /molecular)						
HLA Type	DRB1		DQB1		DPB1	
Antigenic (Serology)						
Allelic (DNA /molecular)						

PATIENT HLA PHENOTYPE:

HLA Type	A		B		C	
Antigenic (Serology)						
Allelic (DNA /molecular)						
HLA Type	DRB1		DQB1		DPB1	
Antigenic (Serology)						
Allelic (DNA /molecular)						

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DISEASE CLASSIFICATION SHEET 1

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
 CIBMTR/ABMTR Code

ACUTE LEUKEMIAS (main disease code 1)

Classification:

AML with recurrent genetic abnormalities

- AML with t(8;21)(q22;q22), (*AML1/ETO*)
- AML with abnormal bone marrow eosinophils and inv(16)(p13q22) or t(16;16)(p13;q22) *CBFβ/MYH11*
- AML with t(15;17)(q22;q12), (*PML/RARα*) and variants (FAB M3)
- AML with 11q23, (*MLL*) abnormalities
- AML with multilineage dysplasia (w/o MDS or MPS/MDS antecedents)

Acute Lymphoblastic Leukemia (ALL)

- Precursor B-cell ALL
- t(9;22)(a34;q11); *BCR/ABL*
- t(v;11q23); *MLL* rearranged
- t(1;19)(q23;p13) *E2A/PBX1*
- t(12;21)(p12'q22) *ETV/CBF-alpha*
- Precursor T-cell ALL
- ALL not otherwise specified

Other Acute Leukemias

- Acute undifferentiated leukaemia
- Biphenotypic, bilineage, hybrid
- Acute mast cell leukaemia
- Other, specify.....

AML not otherwise categorised

- AML, minimally differentiated (FAB M0)
- AML without maturation (FAB M1)
- AML with maturation (FAB M2)
- Acute myelomonocytic leukemia (FAB M4)
- Acute monoblastic/acute monocytic leukemia (FAB M5)
- Acute erythroid leukemia (erythroid/myeloid and pure erythroleukemia) (FAB M6)
- Acute megakaryoblastic leukemia (FAB M7)
- Acute basophilic leukemia
- Acute panmyelosis with myelofibrosis
- Myeloid sarcoma
- AML not otherwise specified

Transformed from MDS → Complete MDS section on Disease Classification Sheet 3. Do not complete the remainder of AML

Secondary origin Yes: Disease related to prior exposure to therapeutic drugs or radiation
 No
 Unknown

Date of this HSCT: - -
yyyy mm dd

Status at HSCT:

STATUS	NUMBER	FOR COMPLETE REMISSION ONLY, TYPE OF REMISSION			
	<i>(complete only for CR or relapse)</i>	No	Yes	Not evaluated	Unknown
<input type="checkbox"/> Primary induction failure					
<input type="checkbox"/> Complete haematological remission (CR)	<input type="checkbox"/> 1 st	Cytogenetic <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Relapse	<input type="checkbox"/> 2 nd	Molecular <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Never treated	<input type="checkbox"/> 3 rd or higher				

CHRONIC MYELOGENOUS LEUKEMIA (CML) (main disease code 2) Note: CMML is not a CML

Classification:

At least one investigation must be positive

Translocation (9;22) Absent Present Not evaluated
 bcr-abl Absent Present Not evaluated

Date of this HSCT: - -
yyyy mm dd

Status at HSCT:

PHASE	NUMBER	FOR CHRONIC PHASE ONLY Presence and type of CR (check all that apply)			
<input type="checkbox"/> Chronic phase (CP)	<input type="checkbox"/> 1 st	Haematological <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown			
<input type="checkbox"/> Accelerated phase	<input type="checkbox"/> 2 nd	Cytogenetic (<i>t(9;22)</i>) <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown			
<input type="checkbox"/> Blast crisis	<input type="checkbox"/> 3 rd or higher	Molecular (<i>bcr-abl</i>) <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown			

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DISEASE CLASSIFICATION SHEET 2

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
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OTHER LEUKEMIAS (main disease code 2)

Classification:

- Chronic lymphocytic leukemia (CLL)
- Polymphocytic Leukemia
- PLL, B-cell
- PLL, T-cell
- Hairy Cell Leukemia
- Other leukemia, specify: _____

Date of this HSCT: - -
yyyy mm dd**Status at HSCT:**

- Stable disease/No response
- Complete remission (CR)
- Partial remission (PR)
- nodular Partial remission (nPR)
- Relapse
- Progression
- Never treated

LYMPHOMAS (main disease code 3)

Classification: Non-Hodgkin's lymphoma (NHL)**B-cell Neoplasms**

- Follicular lymphoma
- Grade I Grade II Grade III Unknown
- Mantle cell lymphoma
- Extranodal marginal zone of MALT type
- Diffuse large B-cell lymphoma (*If known indicate subtype*)
- Intravascular large cell lymphoma
- Mediastinal large cell lymphoma
- Primary effusion large cell lymphoma
- Burkitt's lymphoma/Burkitt cell leukemia (ALL L3)
- High grade B-cell lymphoma, Burkitt-like (provisional entity)
- Lymphoplasmacytic lymphoma
- Waldenstrom macroglobulinaemia
- Splenic marginal zone B-cell lymphoma
- Nodal marginal zone B-cell lymphoma
- Primary CNS lymphoma
- Other B-cell, specify: _____

T-cell & NK-cell Neoplasms

- Angioimmunoblastic (AILD)
- Peripheral T-cell lymphoma (all variants)
- Anaplastic large-cell, T/null cell, primary cutaneous
- Anaplastic large-cell, T/null cell, primary systemic
- Extranodal NK/T-cell lymphoma, nasal type
- Enteropathy-type T-cell lymphoma
- Hepatosplenic gamma-delta T-cell lymphoma
- Subcutaneous panniculitis-like T-cell lymphoma
- Adult T-cell lymphoma/leukaemia (HTLV1+)
- Aggressive NK-cell leukaemia
- Large T-cell granular lymphocytic leukaemia
- Mycosis fungoides
- Sezary syndrome
- Other T/NK-cell, specify: _____

- Hodgkin:** Nodular lymphocyte predominant Lymphocyte rich Nodular sclerosis Mixed cellularity
- Lymphoma depleted Other, specify: _____

Date of this HSCT: - -
yyyy mm dd**Status at HSCT:****STATUS**

- Never treated
- Primary refractory
- Complete remission (CR)
- Confirmed Unconfirmed (CRU*)
- 1st Partial response (PR1)
- Partial response >1 (*never in CR*) (PR>1)
- Relapse
- Progression

NUMBER

- (complete only for CR, PR>1 or relapse)
- 1st
- 2nd
- 3rd or higher

SENSITIVITY TO CHEMOTHERAPY

- (complete only for relapse)
- Sensitive
- Resistant
- Untreated
- unknown

*CRU – complete response with persistent scan abnormalities of unknown significance

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DISEASE CLASSIFICATION SHEET 3

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
 CIBMTR/ABMTR Code

MYELODYSPLASTIC SYNDROME (MDS) (main disease code 6) combined MD/MPS is on separate sheet 4

Please fill in both the WHO and FAB classifications if possible

WHO Classification at diagnosis:

- Refractory anaemia (RA)
- Refractory anaemia with ring sideroblasts (RARS)
- RA with excess of blasts-1 (RAEB-1)
- RA with excess of blasts-2 (RAEB-2)
- Refractory cytopenia with multilineage dysplasia (RCMD)
- RCMD-RS
- MDS associated with isolated del(5q)
- MDS Unclassifiable (MDS-U)

FAB Classification at diagnosis:

- RA
- RARS
- RAEB
- RAEB in transformation (RAEB-t)
- MDS Unclassifiable

- Secondary origin:** Yes: Disease related to prior exposure to therapeutic drugs or radiation
 (other than transformed to AML) No
 Unknown

Please fill in both the WHO and FAB classifications if possible

WHO Classification at HSCT:

- Refractory anaemia (RA)
- Refractory anaemia with ring sideroblasts (RARS)
- RA with excess of blasts-1 (RAEB-1)
- RA with excess of blasts-2 (RAEB-2)
- Refractory cytopenia with multilineage dysplasia (RCMD)
- RCMD-RS
- MDS associated with isolated del(5q)
- Transformed to AML: Date of transformation..... - -
yyyy mm dd
- MDS Unclassifiable (MDS-U)

FAB Classification at HSCT:

- RA
- RARS
- RAEB
- RAEB in transformation (RAEB-t)
- Transformed to AML (fill date in opposite column)
- MDS Unclassifiable

Date of this HSCT: - -
yyyy mm dd

Status at HSCT:

- Treated with chemotherapy:
- Primary refractory phase (no change) **NUMBER** (complete for CR or relapse)
 - Complete remission (CR) 1st
 - Improvement but no CR 2nd
 - Relapse (after CR) 3rd or higher
 - Progression/worse
- Untreated (Supportive care or treatment without chemotherapy)

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DISEASE CLASSIFICATION SHEET 4

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
 CIBMTR/ABMTR Code

Combined Myelodysplastic/Myeloproliferative Neoplasm (MD/MPN) (main disease code 6)

Classification at diagnosis:

- Chronic myelomonocytic leukaemia (CMMoL, CMML)
- Juvenile myelomonocytic leukaemia (JCMMoL, JMML, JCML, JCMML)
- Atypical CML ((t(9;22) negative and bcr/abl negative)

Secondary origin:

(other than transformed to AML)

- Yes: Disease related to prior exposure to therapeutic drugs or radiation
- No
- Unknown

Classification at HSCT:

- Chronic myelomonocytic leukaemia (CMMoL, CMML)
- Juvenile myelomonocytic leukaemia (JCMMoL, JMML, JCML, JCMML)
- Atypical CML ((t(9;22) negative and bcr/abl negative)
- Transformed to AML: Date of transformation..... - -
yyyy mm dd

Date of this HSCT: - -
yyyy mm dd

Status at HSCT:

MDS or CMML (including Transformed to AML) / Atypical CML

Treated with chemotherapy:

- Primary refractory phase (no change) **NUMBER** (complete for CR or relapse)
- Complete remission (CR) 1st
- Improvement but no CR 2nd
- Relapse (after CR) 3rd or higher
- Progression/worse
- Untreated (Supportive care or treatment without chemotherapy)

jMML

- Stable disease (SD)
- Complete response (CR)
- Minimal response (MR)
- Partial response (PR)
- Progression (PD)

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DISEASE CLASSIFICATION SHEET 5

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
 CIBMTR/ABMTR Code

MYELOPROLIFERATIVE SYNDROMES (main disease code 6)

Classification at diagnosis:

- Chronic idiopathic myelofibrosis (primary myelofibrosis, fibrosis with myeloid metaplasia)
- Polycythemia vera
- Essential or primary thrombocythemia
- Hyper eosinophilic syndrome (HES)
- Chronic eosinophilic leukaemia (CEL)
- Chronic neutrophilic leukaemia
- Stem cell leukemia-Lymphoma syndrome (8p11 syndrome)
- MPS not otherwise specified
- Other, specify: _____

Secondary origin:

(other than transformed to AML)

- Yes: Disease related to prior exposure to therapeutic drugs or radiation
- No
- Unknown

Date of this HSCT: - -
yyyy mm dd

Classification at HSCT:

- Chronic idiopathic myelofibrosis (primary myelofibrosis, fibrosis with myeloid metaplasia)
- Polycythemia vera
- Essential or primary thrombocythemia
- Hyper eosinophilic syndrome (HES)
- Chronic eosinophilic leukaemia (CEL)
- Chronic neutrophilic leukaemia
- Stem cell leukemia-Lymphoma syndrome (8p11 syndrome)
- Secondary myelofibrosis: Date of myelofibrosis - -
yyyy mm dd

Transformed to AML: Date of transformation..... - -
yyyy mm dd

- MPS not otherwise specified
- Other, specify: _____

Status at HSCT:

Treated with chemotherapy:

- | | |
|---|--|
| <input type="checkbox"/> Primary refractory phase (no change) | NUMBER (complete for CR or relapse) |
| <input type="checkbox"/> Complete remission (CR) | <input type="checkbox"/> 1 st |
| <input type="checkbox"/> Improvement but no CR | <input type="checkbox"/> 2 nd |
| <input type="checkbox"/> Relapse (after CR) | <input type="checkbox"/> 3 rd or higher |
| <input type="checkbox"/> Progression/worse | |

Untreated (Supportive care or treatment without chemotherapy)

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DISEASE CLASSIFICATION SHEET 6

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
 CIBMTR/ABMTR Code

PLASMA CELL DISORDERS including MULTIPLE MYELOMA (main disease code 4)

Classification	Ig CHAIN TYPE	LIGHT CHAIN TYPE	SALMON & DURIE STAGE AT DIAGNOSIS
<input type="checkbox"/> Multiple myeloma IgG		<input type="checkbox"/> Kappa	(Multiple Myeloma only) <input type="checkbox"/> I and <input type="checkbox"/> A <input type="checkbox"/> II <input type="checkbox"/> B <input type="checkbox"/> III
<input type="checkbox"/> Multiple myeloma IgA		<input type="checkbox"/> Lambda	
<input type="checkbox"/> Multiple myeloma IgD			
<input type="checkbox"/> Multiple myeloma IgE			
<input type="checkbox"/> Multiple myeloma IgM (<i>not Waldenstrom</i>)			
<input type="checkbox"/> Multiple myeloma-light chain only			
<input type="checkbox"/> Multiple myeloma-non-secretory			
<input type="checkbox"/> Plasma cell leukemia			
<input type="checkbox"/> Solitary plasmacytoma			
<input type="checkbox"/> Primary amyloidosis			
<input type="checkbox"/> Other, specify: _____			

Date of this HSCT: - -
yyyy mm dd

Status at HSCT:	NUMBER (<i>complete for CR, PR or relapse</i>)
<input type="checkbox"/> Never treated	<input type="checkbox"/> 1st
<input type="checkbox"/> Complete remission (CR)	<input type="checkbox"/> 2nd
<input type="checkbox"/> Partial remission (PR)	<input type="checkbox"/> 3 rd or higher
<input type="checkbox"/> Minimal response (MR)	
<input type="checkbox"/> Relapse from CR (untreated)	
<input type="checkbox"/> Progression	
<input type="checkbox"/> No change / stable disease	

ANAEMIA (main disease code 7)

Classification:

Acquired Severe Aplastic Anaemia (SAA), not otherwise specified

- Acquired SAA, secondary to hepatitis
- Acquired SAA, secondary to toxin/other drug
- Amegakaryocytosis, acquired (not congenital)
- Acquired Pure Red Cell Aplasia (PRCA) (not congenital)
- Other acquired cytopenic syndrome, specify: _____
- Paroxysmal nocturnal hemoglobinuria (PNH)

Congenital:

- Fanconi anaemia
- Diamond-Blackfan anaemia (congenital PRCA)
- Schwachman-Diamond
- Other congenital anaemia, specify: _____

Date of this HSCT: - -

HAEMOGLOBINOPATHY (main disease code 11)

Classification:

- Thalassemia
- Sickle cell disease
- Other hemoglobinopathy, specify: _____

Date of this HSCT: - -

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DISEASE CLASSIFICATION SHEET 7

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
CIBMTR/ABMTR Code

BREAST CANCER (main disease code 5)

Staging at Diagnosis**METASTASES**

- No distant metastases
 Distant metastasis

STAGE (complete only if No distant metastasis)

- 0 I
 II III

CLASSIFICATION:

- Inflammatory
 Non-inflammatory

Date of this HSCT: - -

Status at HSCT: Adjuvant (Stage II, III only) Never treated (upfront) Primary refractory Complete remission (CR)
 Confirmed Unconfirmed (CRU*)
 Unknown 1st Partial response (PR1) Relapse
 Local Metastatic

*CRU – complete response with persistent scan abnormalities of unknown significance

NUMBER

(complete only for CR or relapse)

- 1st
 2nd
 3rd or higher

SENSITIVITY TO CHEMOTHERAPY

(complete only for relapse)

- Sensitive
 Resistant
 Untreated

OTHER MALIGNANCIES (main disease code 5)

Classification:

- | | |
|---|--|
| <input type="checkbox"/> Bone sarcoma (excluding Ewing sarcoma/PNET) | <input type="checkbox"/> Neuroblastoma |
| <input type="checkbox"/> Central nervous system tumors (include CNS PNET) | <input type="checkbox"/> Ovarian |
| <input type="checkbox"/> Colorectal | <input type="checkbox"/> Pancreas |
| <input type="checkbox"/> Ewing sarcoma/PNET, extra-skeletal | <input type="checkbox"/> Prostate |
| <input type="checkbox"/> Ewing sarcoma/PNET, skeletal | <input type="checkbox"/> Renal cell |
| <input type="checkbox"/> Germ cell tumour, extragonadal only | <input type="checkbox"/> Retinoblastoma |
| <input type="checkbox"/> Hepatobiliary | <input type="checkbox"/> Rhabdomyosarcoma |
| <input type="checkbox"/> Lung cancer, non-small cell | <input type="checkbox"/> Soft tissue sarcoma |
| <input type="checkbox"/> Lung cancer, small cell | <input type="checkbox"/> Testicular |
| <input type="checkbox"/> Medulloblastoma | <input type="checkbox"/> Thymoma |
| <input type="checkbox"/> Melanoma | <input type="checkbox"/> Wilm tumour |
| <input type="checkbox"/> Other, specify | |

Date of this HSCT: - -
yyyy mm dd**Status at HSCT:** Adjuvant Never treated (upfront) Stable disease/no response Complete remission (CR)
 Confirmed Unconfirmed (CRU*)
 1st Partial response (PR1) Relapse Progressive disease (PD)

*CRU – complete response with persistent scan abnormalities of unknown significance

NUMBER

(complete only for CR or relapse)

- 1st
 2nd
 3rd or higher

SENSITIVITY TO CHEMOTHERAPY

(complete only for relapse)

- Sensitive
 Resistant
 Untreated

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DISEASE CLASSIFICATION SHEET 8

PRIMARY IMMUNE DEFICIENCIES (main disease code 8)

Classification:

- | | |
|--|---|
| <input type="checkbox"/> Absence of T and B cells SCID | <input type="checkbox"/> Kostmann syndrome-congenital neutropenia |
| <input type="checkbox"/> Absence of T, normal B cell SCID | <input type="checkbox"/> Leukocyte adhesion deficiencies |
| <input type="checkbox"/> ADA deficiency severe combined immune deficiency (SCID) | <input type="checkbox"/> Neutrophil actin deficiency |
| <input type="checkbox"/> Ataxia telangiectasia | <input type="checkbox"/> Omenn syndrome |
| <input type="checkbox"/> Bare lymphocyte syndrome | <input type="checkbox"/> Reticular dysgenesis |
| <input type="checkbox"/> Cartilage hair hypoplasia | <input type="checkbox"/> SCID other, specify: |
| <input type="checkbox"/> CD 40 Ligand deficiency | <input type="checkbox"/> SCID, unspecified |
| <input type="checkbox"/> Chediak-Higashi syndrome | <input type="checkbox"/> Wiskott Aldrich syndrome |
| <input type="checkbox"/> Chronic granulomatous disease | <input type="checkbox"/> X-linked lymphoproliferative syndrome |
| <input type="checkbox"/> Common variable immunodeficiency | <input type="checkbox"/> Other, specify: |
| <input type="checkbox"/> DiGeorge anomaly | <input type="checkbox"/> Immune deficiencies, not otherwise specified |

Date of this HSCT: - -
yyyy mm dd

INHERITED DISORDERS OF METABOLISM (main disease code 8)

Classification:

- | | |
|--|---|
| <input type="checkbox"/> Adrenoleukodystrophy | <input type="checkbox"/> Metachromatic leukodystrophy |
| <input type="checkbox"/> Aspartyl glucosaminuria | <input type="checkbox"/> Morquio (IV) |
| <input type="checkbox"/> B-glucuronidase deficiency (VII) | <input type="checkbox"/> Mucopolidoses, unspecified |
| <input type="checkbox"/> Fucosidosis | <input type="checkbox"/> Mucopolysaccharidosis (V) |
| <input type="checkbox"/> Gaucher disease | <input type="checkbox"/> Mucopolysaccharidosis, unspecified |
| <input type="checkbox"/> Glucose storage disease | <input type="checkbox"/> Niemann-Pick disease |
| <input type="checkbox"/> Hunter syndrome (II) | <input type="checkbox"/> Neuronal ceroid – lipofuscinosis (Batten disease) |
| <input type="checkbox"/> Hurler syndrome (IH) | <input type="checkbox"/> Polysaccharide hydrolase abnormalities, unspecified |
| <input type="checkbox"/> I-cell disease | <input type="checkbox"/> Sanfilippo (III) |
| <input type="checkbox"/> Krabbe disease (globoid leukodystrophy) | <input type="checkbox"/> Scheie syndrome (IS) |
| <input type="checkbox"/> Lesch-Nyhan (HGPRT deficiency) | <input type="checkbox"/> Wolman disease |
| <input type="checkbox"/> Mannosidosis | <input type="checkbox"/> Other, specify: |
| <input type="checkbox"/> Maroteaux-Lamy (VI) | <input type="checkbox"/> Inherited disorders of metabolism, not otherwise specified |

Date of this HSCT: - -
yyyy mm dd

PLATELET and OTHER INHERITED DISORDERS (main disease code 8)

Classification:

- Glanzmann thrombasthenia
- Congenital amegakaryocytosis / congenital thrombocytopenia
- Other inherited platelet abnormalities, specify: _____
- Osteopetrosis (malignant infantile osteopetrosis)
- Other osteoclast defects, specify: _____

Date of this HSCT: - -
yyyy mm dd

HISTIOCYTIC DISORDERS (main disease code 9)

Classification:

- | | |
|--|---|
| <input type="checkbox"/> Histiocytic disorders, not otherwise specified | <input type="checkbox"/> Familial erythro/hemophagocytic lymphohistiocytosis (FELH) |
| <input type="checkbox"/> Langerhans Cell Histiocytosis (Histiocytosis-X) | <input type="checkbox"/> Hemophagocytosis (reactive or viral associated) |
| <input type="checkbox"/> Malignant histiocytosis | <input type="checkbox"/> Other, specify: _____ |

Date of this HSCT: - -
yyyy mm dd

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DISEASE CLASSIFICATION SHEET 9

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number

CIBMTR/ABMTR Code

Name of Referring Physician

Address

Fax Email

AUTOIMMUNE DISORDERS - I (main disease code 10)

Classification

CONNECTIVE TISSUE DISEASE

 Systemic sclerosis (SS)Date of this HSCT: - -
yyyy mm dd

	Presence	Indication for HSCT
<input type="checkbox"/> diffuse cutaneous	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> limited cutaneous	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> lung parenchyma	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> pulmonary hypertension	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> systemic hypertension	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> renal (biopsy type:.....)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> oesophagus	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> other GI tract	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> Raynaud	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> CREST	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> other, specify:.....	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes

Antibodies studied No

<input type="checkbox"/> Yes: Scl 70 positive	<input type="checkbox"/> Normal/Negative	<input type="checkbox"/> Elevated/Positive	<input type="checkbox"/> Not evaluated
ACA positive	<input type="checkbox"/> Normal/Negative	<input type="checkbox"/> Elevated/Positive	<input type="checkbox"/> Not evaluated

 unknown Systemic lupus erythematosus (SLE)Date of this HSCT: - -
yyyy mm dd

	Presence	Indication for HSCT
<input type="checkbox"/> renal (biopsy type:.....)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> CNS (type:.....)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> PNS (type:.....)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> lung	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> serositis	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> arthritis	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> skin (type:.....)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> haematological (type:.....)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> vasculitis (type:.....)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes
<input type="checkbox"/> other, specify:.....	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes

Antibodies studied No

<input type="checkbox"/> Yes: ds DNA	<input type="checkbox"/> Normal/Negative	<input type="checkbox"/> Elevated/Positive	<input type="checkbox"/> Not evaluated
Complement	<input type="checkbox"/> Normal/Negative	<input type="checkbox"/> Elevated/Positive	<input type="checkbox"/> Not evaluated
Other, specify			

 unknown

HSCT - Minimum Essential Data - A

First report - 100 days after HSCT

DISEASE CLASSIFICATION SHEET 10

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
 CIBMTR/ABMTR Code
 Name of Referring Physician
 Address
 Fax Email

AUTOIMMUNE DISORDERS – II (main disease code 10)

Classification

CONNECTIVE TISSUE DISEASE (CONT.)

Polymyositis- dermatomyositis **Date of this HSCT:** - -
 yyyy mm dd

		Presence		Indication for HSCT	
<input type="checkbox"/>	proximal weakness	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	generalized weakness (including bulbar)	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	pulmonary fibrosis	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	vasculitis (type:.....)	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	other, specify:.....	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes

Manifestation with:

typical biopsy

typical EMG

typical rash (DM)

CPK elevated

malignancy (type:.....)

Sjögren syndrome **Date of this HSCT:** - -
 yyyy mm dd

		Presence		Indication for HSCT	
<input type="checkbox"/>	SICCA	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	exocrine gland swelling	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	other organ lymphocytic infiltration	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	lymphoma, paraproteinemia	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	other, specify:.....	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes

Antiphospholipid syndrome **Date of this HSCT:** - -
 yyyy mm dd

		Presence		Indication for HSCT	
<input type="checkbox"/>	thrombosis (type:.....)	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	CNS (type:.....)	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	abortion	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	skin (livido, vasculitis)	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	hematological (type:.....)	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes
<input type="checkbox"/>	other, specify:.....	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes

Antibodies studied No

Yes: Anticardiolipin IgG Normal/Negative Elevated/Positive Not evaluated

Anticardiolipin IgM Normal/Negative Elevated/Positive Not evaluated

Other, specify

unknown

Other type of connective tissue disease, specify:.....

Date of this HSCT: - -
 yyyy mm dd

HSCT - Minimum Essential Data - A

First report - 100 days after HSCT

DISEASE CLASSIFICATION SHEET 11

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number

CIBMTR/ABMTR Code

Name of Referring Physician

Address

Fax Email

AUTOIMMUNE DISORDERS – III (main disease code 10)

Classification**VASCULITIS** Wegener granulomatosisDate of this HSCT: - -
yyyy mm dd

- upper respiratory tract
 pulmonary
 renal (biopsy type:.....)
 skin
 other, specify:.....

Presence

- No Yes
 No Yes
 No Yes
 No Yes
 No Yes

Indication for HSCT

- No Yes
 No Yes
 No Yes
 No Yes
 No Yes

Antibodies studied No Yes: c-ANCA Negative Positive Not evaluated unknown Classical polyarteritis nodosa Classical MicroscopicDate of this HSCT: - -
yyyy mm dd

- renal (type:.....)
 mononeuritis multiplex
 pulmonary haemorrhage
 skin
 GI tract
 other, specify:.....

Presence

- No Yes
 No Yes
 No Yes
 No Yes
 No Yes
 No Yes

Indication for HSCT

- No Yes
 No Yes
 No Yes
 No Yes
 No Yes
 No Yes

Antibodies studied No Yes: p-ANCA Negative Positive Not evaluated

c-ANCA

 Negative Positive Not evaluated

Hepatitis serology

 Negative Positive Not evaluated unknown

Other vasculitis:

 Churg-Strauss Giant cell arteritis Takayasu Behçet's syndrome Overlap necrotising arteritis Other, specify:.....Date of this HSCT: - -
yyyy mm dd

HSCT - Minimum Essential Data - A

First report - 100 days after HSCT

DISEASE CLASSIFICATION SHEET 12

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number

CIBMTR/ABMTR Code

Name of Neurologist / Referring Physician

Address

Fax Email

AUTOIMMUNE DISORDERS - IV (main disease code 10)

ARTHRITIS Rheumatoid arthritisDate of this HSCT: - -
yyyy mm dd destructive arthritis**Presence** No Yes**Indication for HSCT** No Yes necrotising vasculitis No Yes No Yes eye (type:)) No Yes No Yes pulmonary No Yes No Yes extra articular (specify:)) No Yes No Yes other, specify: No Yes No Yes Psoriatic arthritis/psoriasisDate of this HSCT: - -
yyyy mm dd destructive arthritis**Presence** No Yes**Indication for HSCT** No Yes psoriasis No Yes No Yes other, specify: No Yes No Yes Juvenile idiopathic arthritis (JIA), systemic (Stills disease) Juvenile idiopathic arthritis (JIA), articular: Onset Oligoarticular
 Polyarticular Juvenile idiopathic arthritis: other, specify: Other arthritis:Date of this HSCT: - -
yyyy mm dd**MULTIPLE SCLEROSIS** Multiple sclerosisDate of this HSCT: - -
yyyy mm dd primary progressive secondary progressive relapsing/remitting other:**OTHER NEUROLOGICAL AUTOIMMUNE DISEASE** Myasthenia gravis Other autoimmune neurological disorder, specify:Date of this HSCT: - -
yyyy mm dd**HAEMATOLOGICAL AUTOIMMUNE DISEASES** Idiopathic thrombocytopenic purpura (ITP) Hemolytic anemia Evan syndrome other autoimmune cytopenia, specify:Date of this HSCT: - -
yyyy mm dd**BOWEL DISEASE** Crohn's disease Ulcerative colitis Other autoimmune bowel disease, specify:Date of this HSCT: - -
yyyy mm dd

HSCT - Minimum Essential Data - A

Follow up report: 1 year post transplant and annually thereafter

PRIMARY DISEASE DIAGNOSIS.....

CENTRE IDENTIFICATION

EBMT Code (CIC):

CIBMTR/ABMTR Code

Hospital:

Unit:

Contact person.....

REPORT INFORMATION

Date of this Report: - -
 yyyy mm dd

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

Name of study / trial

PATIENT AND TRANSPLANT IDENTIFICATION

Unique Patient Number or Code:
 (Compulsory, registrations will not be accepted without this item)

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

Date of Birth: - -
 yyyy mm dd

Sex: Male Female

Date of the most recent transplant before this follow up:
 - -
 yyyy mm dd

DISEASE STATUS

Best disease status (response) after transplant
 (prior to treatment modification in response to a post transplant disease assessment)

Continued complete remission (CR)

CR achieved: Date achieved : - -
 yyyy mm dd

Never in CR: Date assessed: - -
 yyyy mm dd

Previously reported - -
 yyyy mm dd

DATE OF LAST CONTACT

Date of last follow up or death: - -
 yyyy mm dd

COMPLICATIONS OF TRANSPLANT

Late graft failure No Yes

Chronic Graft Versus Host Disease present during this period
 (allografts only)

No (never)

Yes: First episode since last HSCT
 Date of diagnosis of cGVHD:
 - -
 yyyy mm dd

Recurrence
 Date first evidence of cGVHD during this period:
 - -
 yyyy mm dd

Continuous since last reported episode

Maximum extent during this period
 Limited Extensive Unknown

Resolved since last report (currently absent)

Did a secondary malignancy, lymphoproliferative or myeloproliferative disorder occur?

No Yes:
 Date of diagnosis: - -
 yyyy mm dd

Diagnosis:

ADDITIONAL TREATMENT

No Yes: Date - -
 yyyy mm dd

If yes: Additional cell infusion
 No Yes: **Attach the CI sheet completing as many sections as necessary**

Other disease treatment
 No Yes: Planned (planned before transplant)
 Not planned (for relapse/progression or persistent disease)

FIRST RELAPSE OR PROGRESSION

First Relapse or Progression after HSCT (Any type)
 No Yes Continuous progression since HSCT

If **yes** or **continuous progression** and for acute and chronic **LEUKAEMIAS** only, tick all methods used for assessment with the dates on which they were used and the results.

Relapse/progression detected by clinical/haematological method:

No: Date assessed - -
 yyyy mm dd

Yes: Date first seen - -
 Previously reported - -
 yyyy mm dd

Not evaluated

Relapse/progression detected by cytogenetic method:

No: Date assessed - -
 yyyy mm dd

Yes: Date first seen - -
 Previously reported - -
 yyyy mm dd

Not evaluated

Relapse/progression detected by molecular method:

No: Date assessed - -
 yyyy mm dd

Yes: Date first seen - -
 Previously reported - -
 yyyy mm dd

Not evaluated

DISEASE PRESENCE/DETECTION AT LAST CONTACT

Last disease status (record the most recent status and date for each method, depending on the disease)

Was disease detected by clinical/haematological method?:

No Yes
 Last date assessed - -
 yyyy mm dd

Not evaluated

Fill in only for acute and chronic **LEUKAEMIAS**

Was disease detected by cytogenetic/FISH method?:

No Yes:
 Considered disease relapse/progression: No Yes
 Last date assessed - -
 yyyy mm dd

Not evaluated

Fill in only for acute and chronic **LEUKAEMIAS**

Was disease detected by molecular method?:

No Yes:
 Considered disease relapse/progression No Yes
 Last date assessed - -
 yyyy mm dd

Not evaluated

CONCEPTION

Has patient or partner become pregnant after this transplant?
 Yes No Unknown

PATIENT STATUS

Survival Status:
 Alive Dead

Check here if patient lost to follow up

Main Cause of Death (check only one main cause):

Relapse or Progression/Persistent disease
 Secondary malignancy
 HSCT Related Cause
 (check as many as appropriate):

GVHD Cardiac Toxicity
 Rejection/Poor graft function Infection
 Pulmonary toxicity Veno occlusive disorder
 Post transplant lymphoproliferative disorder
 Other:.....
 Unknown
 Other:

HSCT - Minimum Essential Data - A

Follow up report: Annual follow up

CELL INFUSION (CI) SHEET

EBMT Centre Identification Code (CIC) Hospital Unique Patient Number
 CIBMTR Code

CELL INFUSION

Date of first infusion:
 yyyy mm dd

Disease status before this CI CR Not in CR Not evaluated

Cell infusion (CI) regimen (not HSCT or autologous stem cell re-infusion)
 Type of cell(s): (check all that apply)
 Lymphocytes Mesenchymal Fibroblasts Dendritic cells Other, specify

Chronological no. of CI for this patient

Indication: Planned Prophylactic Mixed chimaerism
 (check all that apply) Loss / decreased chimaerism Treatment of GvHD Treatment for disease
 Treatment PTLD, EBV lymphoma Treatment viral infection 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 / transplant):
 Maximum Grade: 0 (none) 1 2 3 4 Present but grade unknown

CELL INFUSION

Date of first infusion:
 yyyy mm dd

Disease status before this CI CR Not in CR Not evaluated

Cell infusion (CI) regimen (not HSCT or autologous stem cell re-infusion)
 Type of cell(s): (check all that apply)
 Lymphocytes Mesenchymal Fibroblasts Dendritic cells Other, specify

Chronological no. of CI for this patient

Indication: Planned Prophylactic Mixed chimaerism
 (check all that apply) Loss / decreased chimaerism Treatment of GvHD Treatment for disease
 Treatment PTLD, EBV lymphoma Treatment viral infection 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 / transplant):
 Maximum Grade: 0 (none) 1 2 3 4 Present but grade unknown

CELL INFUSION

Date of first infusion:
 yyyy mm dd

Disease status before this CI CR Not in CR Not evaluated

Cell infusion (CI) regimen (not HSCT or autologous stem cell re-infusion)
 Type of cell(s): (check all that apply)
 Lymphocytes Mesenchymal Fibroblasts Dendritic cells Other, specify

Chronological no. of CI for this patient

Indication: Planned Prophylactic Mixed chimaerism
 (check all that apply) Loss / decreased chimaerism Treatment of GvHD Treatment for disease
 Treatment PTLD, EBV lymphoma Treatment viral infection 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 / transplant):
 Maximum Grade: 0 (none) 1 2 3 4 Present but grade unknown

CELL INFUSION

Date of first infusion:
 yyyy mm dd

Disease status before this CI CR Not in CR Not evaluated

Cell infusion (CI) regimen (not HSCT or autologous stem cell re-infusion)
 Type of cell(s): (check all that apply)
 Lymphocytes Mesenchymal Fibroblasts Dendritic cells Other, specify

Chronological no. of CI for this patient

Indication: Planned Prophylactic Mixed chimaerism
 (check all that apply) Loss / decreased chimaerism Treatment of GvHD Treatment for disease
 Treatment PTLD, EBV lymphoma Treatment viral infection 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 / transplant):
 Maximum Grade: 0 (none) 1 2 3 4 Present but grade unknown