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IMMUNOSUPPRESSIVE TREATMENT (IST) --- Annual/Unscheduled Follow-Up ---

SURVIVAL STATUS

Date of follow-up: ____/____/____ (YYYY/MM/DD)
(if died: date of death, if lost to follow up: date last seen)

Survival status:

- Alive
- Dead
- Lost to follow-up

Date of the last IST for this patient: ____/____/____ (YYYY/MM/DD)

BEST RESPONSE

Best response since the last follow-up (even if the response got worse again afterwards):

- Stable disease / No change / No response
- Complete remission (CR)
- Partial remission (PR)
- Haematological improvement (HI); *NIH partial response*
- Relapse / Progression
- Not evaluated
- Unknown

Date best response observed: ____/____/____ (YYYY/MM/DD) Unknown

Transfusions since last follow-up:

- | | | | |
|------------|--|-----------------------|----------------------------------|
| RBC: | <input type="checkbox"/> < 20 units | RBC irradiated: | <input type="checkbox"/> No |
| | <input type="checkbox"/> 20 - 50 units | | <input type="checkbox"/> Yes |
| | <input type="checkbox"/> > 50 units | | <input type="checkbox"/> Unknown |
| | <input type="checkbox"/> None | | |
| | <input type="checkbox"/> Unknown | | |
| | | | |
| Platelets: | <input type="checkbox"/> < 20 units | Platelets irradiated: | <input type="checkbox"/> No |
| | <input type="checkbox"/> 20 - 50 units | | <input type="checkbox"/> Yes |
| | <input type="checkbox"/> > 50 units | | <input type="checkbox"/> Unknown |
| | <input type="checkbox"/> None | | |
| | <input type="checkbox"/> Unknown | | |

FIRST RELAPSE AFTER IST

Complete this section only for the first relapse after this IST.

First relapse/progression of Aplastic Anaemia (detected by any method):

- No
- Yes: **Date of relapse:** ____/____/____ (YYYY/MM/DD)

LAST DISEASE STATUS

Disease status this follow-up:

(disease status on the date the patient was last assessed)

- Stable disease / No change / No response
- Complete remission (CR)
- Partial remission (PR)
- Haematological improvement (HI); *NIH Partial Response*
- Relapse / Progression
- Not evaluated
- Unknown

COMPLICATIONS SINCE LAST FOLLOW-UP

Adverse events/non-infectious complications grade 2-5 observed *(based on CTCAE grades):*

- No
- Yes (provide details in the table below)

Adverse event	Observed?	Maximum CTCAE grade observed	Onset date (YYYY/MM/DD)
Idiopathic pneumonia syndrome	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Veno-occlusive disease (VOD)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Cataract	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Haemorrhagic cystitis, non-infectious	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
ARDS, non-infectious	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Multiorgan failure, non-infectious	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Renal failure (chronic kidney disease, acute kidney injury)	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Haemolytic anaemia due to blood group	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Aseptic bone necrosis	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Liver disorder	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Cardiovascular event	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Stroke	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Central nervous system (CNS) toxicity	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Endocrine event	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____
Other; specify: _____		<input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (fatal) <input type="checkbox"/> Unknown	____/____/____

SECONDARY MALIGNANCIES AND AUTOIMMUNE DISORDERS

Did a secondary malignancy or autoimmune disorder occur?

- No
- Yes: was this disease an indication for a subsequent HCT/CT/IST?
- No (complete the non-indication diagnosis form)
 - Yes (complete the relevant indication diagnosis form)

BONE MARROW INVESTIGATION

Bone marrow investigation:

- No
- Yes: Date of bone marrow investigation: ____/____/____ (YYYY/MM/DD)

Type of bone marrow investigation:

- Cytology
- Histology
- Both

Type of dysplasia:

- | | | | | |
|-------------------------|-----------------------------|------------------------------|--|----------------------------------|
| Erythroid dysplasia | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Granulocyte dysplasia | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |
| Megakaryocyte dysplasia | <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> Not evaluated | <input type="checkbox"/> Unknown |

Bone marrow assessments:

Cellularity in the bone marrow aspirate	<input type="checkbox"/> Acellular <input type="checkbox"/> Hypocellular <input type="checkbox"/> Normocellular <input type="checkbox"/> Hypercellular	<input type="checkbox"/> Focal cellularity <input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
Cellularity in the bone marrow trephine	<input type="checkbox"/> Acellular <input type="checkbox"/> Hypocellular <input type="checkbox"/> Normocellular <input type="checkbox"/> Hypercellular	<input type="checkbox"/> Focal cellularity <input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
Fibrosis on bone marrow biopsy	<input type="checkbox"/> No <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe	<input type="checkbox"/> Not evaluable <input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
CD34+ cell count	_____ %	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown
Blast count	_____ %	<input type="checkbox"/> Not evaluated <input type="checkbox"/> Unknown

CHROMOSOME ANALYSIS

Chromosome analysis done at follow-up (all methods including FISH):

- Not done or failed
- Yes, abnormal results
- Yes, normal results
- Unknown

Date of chromosome analysis (if applicable): ____/____/____ (YYYY/MM/DD)

Indicate below whether the abnormalities were absent, present or not evaluated.

Trisomy 8	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
abn 3	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
Monosomy 7	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
del(13q)	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
Other; specify: _____	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	

MOLECULAR MARKER ANALYSIS

Molecular marker analysis done at follow-up:

- No
- Yes
- Unknown

Date of molecular marker analysis (if applicable): ____/____/____ (YYYY/MM/DD)

Indicate below whether the markers were absent, present or not evaluated.

ASXL1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
BCOR	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
BCORL1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
CBL	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
CSMD1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
DNMT3A	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
ETV6	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
EZH2	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
FLT3	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
GNAS	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
IDH1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
IDH2	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
JAK2	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
KRAS	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
MPL	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
NPM1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
NRAS	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
PHF6	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated

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MOLECULAR MARKER ANALYSIS continued

PIGA	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
PPM1D	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
PTPN11	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
RAD21	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
RUNX1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
SETBP1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
SF3B1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
SRSF2	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
STAG2	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
TET2	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
TP53	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
U2AF1	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated
ZRSR2	<input type="checkbox"/> Absent	<input type="checkbox"/> Present	<input type="checkbox"/> Not evaluated

PNH TESTS SINCE LAST FOLLOW-UP

PNH test done:

- No
 Yes: **Date of PNH test:** ____/____/____ (YYYY/MM/DD) Unknown

PNH diagnostics by flow cytometry:

- Clone absent
 Clone present: Size of PNH clone in %: _____

Flow cytometry assessment done on:

- Granulocytes
 RBC
 Both
 Other; specify: _____

PNH TESTS SINCE LAST FOLLOW-UP continued

Clinical manifestation of PNH:

- No
 Yes: **Date of clinical manifestation:** ____/____/____ (YYYY/MM/DD) Unknown

Anti-complement treatment given?

- No
 Yes, complete the table:

Drug	Start date (YYYY/MM/DD)	Stop date (YYYY/MM/DD)
<input type="checkbox"/> Eculizumab	____/____/____ <input type="checkbox"/> Unknown	____/____/____ <input type="checkbox"/> Ongoing <input type="checkbox"/> Unknown
<input type="checkbox"/> Ravulizumab	____/____/____ <input type="checkbox"/> Unknown	____/____/____ <input type="checkbox"/> Ongoing <input type="checkbox"/> Unknown
<input type="checkbox"/> Pegcetacoplan	____/____/____ <input type="checkbox"/> Unknown	____/____/____ <input type="checkbox"/> Ongoing <input type="checkbox"/> Unknown
<input type="checkbox"/> Other; specify*: _____	____/____/____ <input type="checkbox"/> Unknown	____/____/____ <input type="checkbox"/> Ongoing <input type="checkbox"/> Unknown

*Please consult the **LIST OF CHEMOTHERAPY DRUGS/AGENTS AND REGIMENS** on the EBMT website for drugs/regimens names
If there were more drugs given during one line of treatment add more copies of this page.

CAUSE OF DEATH

Main cause of death:

(check only one main cause)

<input type="checkbox"/> Relapse or progression/persistent disease	
<input type="checkbox"/> Secondary malignancy	
<input type="checkbox"/> Cellular therapy-related	Select treatment related cause: <input type="checkbox"/> Graft versus Host Disease <input type="checkbox"/> Non-infectious complication <input type="checkbox"/> Infectious complication: <i>(select all that apply)</i> <input type="checkbox"/> Bacterial infection <input type="checkbox"/> Viral infection <input type="checkbox"/> Fungal infection <input type="checkbox"/> Parasitic infection <input type="checkbox"/> Infection with unknown pathogen
<input type="checkbox"/> HCT-related	
<input type="checkbox"/> IST-related	
<input type="checkbox"/> Unknown	
<input type="checkbox"/> Other; specify: _____	