

MPN Childhood Registry - Yearly Follow-up Visit

General data:

Patient number: | _____ |

Date of birth: | _____ | (dd.mm.yy)

Gender: female male

Diagnosis: | _____ | (ET/PV/PMF/pHES)

Visit date: | _____ | (dd.mm.yy)

Body weight (kg) at time of visit | _____ |

Height (cm) at time of visit | _____ |

Treating Center: | _____ |

Treating physician: | _____ |
name phone e mail

Study nurse: | _____ |
name phone e mail

Patient alive at this visit: no yes

If no day of death: | _____ | (dd.mm.yy)

If no cause of death: | _____ |

If no date of last visit: | _____ | (dd.mm.yy)

Therapy continued at another hospital/institution: no yes

If yes, name of the insitution: | _____ |

Course of disease:

Stable disease: no yes

If no specify: | _____ | (progression/transformation)

Disease-associated complications: no yes

If yes specify: | _____ | (thrombosis/haemorrhage/other)

| _____ |
 | _____ |

General performance (Lansky performance status):

| ____ | %, date | _____ | (dd.mm.yy)



Symptoms:

Hematological:

- Anemia no yes, CTCAE grade | ____ |
 Neutropenia no yes, CTCAE grade | ____ |
 Thrombocytopenia no yes, CTCAE grade | ____ |

Non-hematological:

- Skin rash no yes, CTCAE grade | ____ |
 Nausea no yes, CTCAE grade | ____ |
 Vomiting no yes, CTCAE grade | ____ |
 Diarrhea no yes, CTCAE grade | ____ |
 Edema no yes, CTCAE grade | ____ |
 Muscle cramps no yes, CTCAE grade | ____ |
 Headache no yes, CTCAE grade | ____ |
 LFT elevation no yes, CTCAE grade | ____ |
 Infection no yes, specify: | _____ | CTCAE grade | ____ |
 Other no yes, specify: | _____ | CTCAE grade | ____ |

MPN-specific treatment: no yes

If yes specify:

- Hydroxyurea no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Anagrelide no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Interferon alpha no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Ruxolitinib no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Phlebotomy no yes, from | ____ | until | ____ | (dd.mm.yy); Amount: | ____ | (ml)
 Corticosteroids no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Other no yes

If yes specify: | ____ | from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)

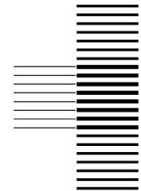
Transplantation no yes

If yes (scheduled) date: | ____ | (dd.mm.yy)

Concomitant treatment: no yes

If yes specify:

- Aspirin no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Vitamin K Antagonist no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Low molecular weight heparin no yes, from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)
 Other no yes
 If yes specify: | ____ | from | ____ | until | ____ | (dd.mm.yy); Dose: | ____ | (mg)


Clinical examination

 Organomegaly no yes

 If yes: Spleen size below costal margin by palpation |_____| cm
 Liver size below costal margin by palpation |_____| cm

 Spleen size by ultrasound |_____| cm
 Liver size by ultrasound |_____| cm

 Additional clinical findings no yes

If yes specify: |_____|

|_____|

Laboratory analyses at time of visit:

(provide only if not performed at the reference centers Erlangen or Hannover)

Peripheral blood	
Date	(dd.mm.yy)
Leukocyte count	($10^9/l$)
Hemoglobin	<input type="checkbox"/> g/dl <input type="checkbox"/> mmol/l
Hematocrit	(%)
Erythrocytes	($10^{12}/l$)
MCV	(fl)
Thrombocytes	($10^9/l$)

Differentiation	Peripheral blood (%)	Bone marrow (%)
Blasts lymphatic		
Blasts myeloid		
Promyelocytes		
Myelocytes		
Metamyelocytes		
Rod neutrophils		
Segmented neutrophils		
Eosinophils		
Basophils		
Monocytes		
Lymphocytes		
Total granulopoiesis		
Proerythroblasts		
Basophilic erythroblasts		
Polychromatic erythroblasts		
Orthochromatic erythroblasts		
Total erythropoiesis		



Bone marrow biopsy: Date | _____ | (dd/mm/yy)

Location of laboratory | _____ |

Cellularity | _____ | (%) Grade of fibrosis | _____ | (0-3)

Cytogenetic analysis of bone marrow: Date | _____ | (dd/mm/yy)

Location of laboratory | _____ |

Method G-banding (interphase; metaphase) FISH

Number of metaphases analysed | _____ |

Karyotype
| _____ |

Molecular analyses: Date | _____ | (dd/mm/yy)

Location of laboratory | _____ |

from bone marrow; from peripheral blood

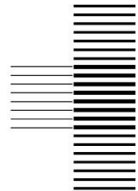
Result
| _____ |

Clinical Chemistry	Value	Unit
Bilirubin		
ALAT		
ASAT		
Gamma-GT		
LDH		
Uric Acid		
Creatinine		
Alkaline Phosphatase		

HLA-typing performed: no yes

Adverse events no yes

If yes specify: | _____ |
| _____ |



Remarks:

Date

Name

Signature