

MPN Childhood Registry - Initial Visit at Diagnosis

General data:

Patient number: | _____ |

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

Gender: female male

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

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

Treating Center: | _____ |

Treating physician: | _____ |
name phone e mail

Study nurse: | _____ |
name phone e mail

Written informed consent for electronic management of patient data was given:

no yes | _____ | (dd.mm.yy)

Pre-treatment in another hospital:

no yes, in | _____ |

Reason for diagnosis:

- Incidental detection of MPN
- Disease-related symptoms caused contact with physician; specify | _____ |
- Scheduled health supervision visit

Condition at presentation:

Fatigue no yes

Headache no yes

Fever (> 38 °C) no yes

Active infection no yes

If yes specify: | _____ |



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

Lymphadenopathy no yes

If yes specify: |_____||

Thrombosis no yes

If yes specify: |_____|| CTCAE grade | ____|

Bleeding no yes

If yes specify: |_____|| CTCAE grade | ____|

Other no yes

If yes specify: |_____|| CTCAE grade | ____|

Body weight (kg) at diagnosis |_____|

Recent loss of body weight no yes

If yes specify: |_____||

Height (cm) at diagnosis |_____|

Head circumference (cm) at diagnosis |_____|

Patient is twin no yes

If yes: monozygotic dizygotic

Pregnancy no yes

if yes gestational week: |_____||

Organ dysfunctions: no yes

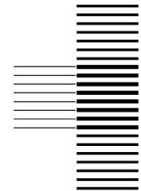
If yes specify: |_____|| CTCAE grade | ____|

|_____|| CTCAE grade | ____|

|_____|| CTCAE grade | ____|

General performance (Lansky performance status):

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


Past medical history:

 Medical treatment non MPN-related no yes

If yes specify: | _____ |

 Hospitalizations/surgeries no yes

if yes specify: | _____ |

 Consumption of any drugs no yes

If yes specify (substances including amount/duration/frequency):

| _____ |

Other pathologies:

 Previous malignancy no yes

If yes specify: | _____ |

Date of diagnosis | _____ | (dd/mm/yy)

 Previous chemo-radiotherapy no yes

If yes specify: | _____ |

 Mental retardation no yes

 Birth weight < 2500 g no yes

 Head circumference
< 3rd percentile no yes

 Height < 3rd percentile no yes

 Weight < 3rd percentile no yes

 Syndrome / inherited disorder no yes

If yes specify: | _____ |

 Other abnormalities no yes

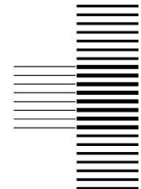
If yes specify: | _____ |

Family history in 1st° relatives:

 Parents are cousins no yes

 Family history of malignancy no yes

 If yes specify: | _____ |
| _____ |


 Other possibly relevant disease no yes

If yes specify: | _____ |

| _____ |

Laboratory analyses at diagnosis:

(provide only if not performed at the reference centers Erlangen and Hanover)

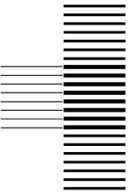
Peripheral blood	
Date	(dd.mm.yy)
Leukocyte count	($10^9/l$)
Hemoglobin	<input type="checkbox"/> g/dl <input type="checkbox"/> mmol/l
Hematocrit	(%)
Erythrocytes	($10^{12}/l$)
MCV	(fl)
Thrombocytes	($10^9/l$)

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 erythroblast		
Orthochromatic erythroblast		
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

MPN-specific treatment initiated: no yes

If yes specify: | _____ |

Date of treatment initiation: | _____ | (dd/mm/yy)

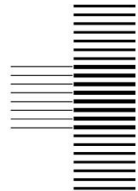
Dosage: | _____ | absolute per kg BW per m² BSA

Concomitant treatment initiated: no yes

If yes specify: | _____ |

Date of treatment initiation: | _____ | (dd/mm/yy)

Dosage: | _____ | absolute per kg BW per m² BSA



Remarks:

Date

Name

Signature