



**MPN Childhood Registry Visitenbogen initial**

Formular

**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
- Tumor-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: | \_\_\_\_\_ |



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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:  monozygotisch  dizygotisch

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)



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**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 < 3<sup>rd</sup> percentile  no  yes

Height < 3<sup>rd</sup> percentile  no  yes

Weight < 3<sup>rd</sup> 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: | \_\_\_\_\_ |  
| \_\_\_\_\_ |



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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 <sup>9</sup> /l)
Hemoglobin	<input type="checkbox"/> g/dl <input type="checkbox"/> mmol/l
Hematocrit	(%)
Erythrocytes	(10 <sup>12</sup> /l)
MCV	(fl)
Thrombocytes	(10 <sup>9</sup> /l)

Differentiation	Peripheral blood (%)	Bone marrow (%)
Blasts lymphatic		
Blasts myeloid		
Promyelocytes		
Myelocytes		
Metamyelocytes		
Rod neutrophils		
Segmented neutrophils		
Eosinophils		
Basophils		
Monocytes		
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)



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**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 m<sup>2</sup> BSA

**Concomitant treatment initiated:**  no  yes

If yes specify: | \_\_\_\_\_ |

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

Dosage: | \_\_\_\_\_ |  absolute  per kg BW  per m<sup>2</sup> BSA



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Remarks:

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**Date**

**Name**

**Signature**