MPN Childhood Registry - Yearly Follow-up Visit

General data:

Patient number: I_____I

Date of birth: I_____I (dd.mm.yy)

Gender: ☐ female ☐ male

Diagnosis: I_____I (ET/PV/PMF/pHES)

Visit date: I_____I (dd.mm.yy)

Body weight (kg) at time of visit I _____I

Height (cm) at time of visit I _____I

Treating Center: I_____I

Treating physician: I_____I
name phone e mail

Study nurse: I_____I
name phone e mail

Patient alive at this visit: ☐ no ☐ yes
If no day of death: I_____I (dd.mm.yy)

If no cause of death: I_____I

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

Therapy continued at another hospital/institution: ☐ no ☐ yes
If yes, name of the insitution: I_____I

Course of disease:
Stable disease: ☐ no ☐ yes
If no specify: I_____I (progression/transformation)

Disease-associated complications: ☐ no ☐ yes
If yes specify: I_____I (thrombosis/haemorrhage/other)
I_____I
I_____I

General performance (Lansky performance status):

I ____I %, date I_____I (dd.mm.yy)

Symptoms:

Hematological:

Anemia ☐ no ☐ yes, CTCAE grade I ____I
Neutropenia ☐ no ☐ yes, CTCAE grade I ____I
Thrombocytopenia ☐ no ☐ yes, CTCAE grade I ____I

Non-hematological:

Skin rash ☐ no ☐ yes, CTCAE grade I ____I
Nausea ☐ no ☐ yes, CTCAE grade I ____I
Vomiting ☐ no ☐ yes, CTCAE grade I ____I
Diarrhea ☐ no ☐ yes, CTCAE grade I ____I
Edema ☐ no ☐ yes, CTCAE grade I ____I
Muscle cramps ☐ no ☐ yes, CTCAE grade I ____I
Headache ☐ no ☐ yes, CTCAE grade I ____I
LFT elevation ☐ no ☐ yes, CTCAE grade I ____I
Infection ☐ no ☐ yes, specify: I_____I CTCAE grade I ____I
Other ☐ no ☐ yes, specify: I_____I CTCAE grade I ____I

MPN-specific treatment: ☐ no ☐ yes

If yes specify:

Hydroxyurea ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Anagrelide ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Interferon alpha ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Ruxolitinib ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Phlebotomy ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Amount: I_____I (ml)

Corticosteroids ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Other ☐ no ☐ yes

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

Transplantation ☐ no ☐ yes

If yes (scheduled) date: I_____I (dd.mm.yy)

Concomitant treatment: ☐ no ☐ yes

If yes specify:

Aspirin ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Vitamin K Antagonist ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Low molecular weight heparin ☐ no ☐ yes, from I_____I until I_____I (dd.mm.yy); Dose: I_____I (mg)

Other ☐ no ☐ yes
If yes specify: I_____I from I_____I until I_____I (dd.mm.yy); Dose: I_____I (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: I_____I

I_____I

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	☐ g/dl ☐ 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 granulopoesis		
Proerythroblasts		
Basophilic erythroblasts		
Polychromatic erythroblasts		
Orthochromatic erythroblasts		
Total erythropoesis		

Bone marrow biopsy: Date I_____I (dd/mm/yy)

Location of laboratory I_____I

Cellularity I_____I (%) Grade of fibrosis I_____I (0-3)

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

Location of laboratory I_____I

Method ☐ G-banding (☐ interphase; ☐ metaphase) ☐ FISH

Number of metaphases analysed I_____I

Karyotype
I_____I

Molecular analyses: Date I_____I (dd/mm/yy)

Location of laboratory I_____I

☐ from bone marrow; ☐ from peripheral blood

Result
I_____I

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: I_____I

I_____I

Remarks:

Date	Name	Signature