EWOG MDS - 2006

Initial Registration

Patient Name |_____|

Patient identification number |_____|

Sex ☐ male ☐ female

Date of Birth (dd/mm/yy) |__|__||__|__||__|__|

Please make sure that the consent form is signed before transmitting these data!

Date of onset (dd/mm/yy) |__|__||__|__||__|__|

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

Clinical features and physical examination at diagnosis

	no	yes		
Fatigue	☐	☐		
Fever (> 38° C)	☐	☐		
Active infection	☐	☐		
Respiratory tract symptoms	☐	☐		
Bleeding	☐	☐	if yes, site	
Lymphadenopathy (>1.5 cm)	☐	☐		
Skin rash	☐	☐	if yes, site	
Enlarged tonsils	☐	☐		
Chloroma	☐	☐	if yes, site	
Diabetes insipidus	☐	☐		
Blasts in CSF	☐	☐	if yes,	l_____l leukocytes/µl
	☐	not examined (for JMML or RC lumbar puncture not necessary)		
Other signs or symptoms	☐	☐	if yes, specify	

Spleen size below costal margin by palpation l_____l cm

Liver size below costal margin by palpation l_____l cm

Associated pathology / medical history of the patient

	no	yes	
Xanthoma	☐	☐	
"Cafe au lait" spots	☐	☐	prepubertal children > 5mm (greatest diameter)
			☐ < 10 spots give exaxt number ___
			☐ ≥ 10
		☐	postpubertal children > 15mm (greatest diameter)
			☐ < 10 spots give exaxt number ___
			☐ ≥ 10
other symptoms of NF1	☐	☐	neurofibromas of any type
		☐	plexiform neurofibroma
		☐	freckling in the axillary or inguinal regions
		☐	optic glioma
		☐	≥ 2 Lisch nodules of the iris
		☐	osseous lesions associated with NF1
1° relatives with NF1	☐	☐	if yes, ☐mother ☐father ☐sister ☐brother ☐other
	☐ unknown		
Previous congenital bone marrow failure disorder	☐	☐	if yes, specify I_____I
Previous acquired bone marrow disorder	☐	☐	Date of diagnosis (dd/mm/yy) |__|__||__|__||__|__| if yes, specify I_____I
Previous malignancy	☐	☐	if yes, specify I_____I Date of diagnosis (dd/mm/yy) |__|__||__|__||__|__|
Previous chemo-radiotherapy	☐	☐	if yes, specify I_____I
Mental retardation	☐	☐	
Birth weight < 2500 g	☐	☐	
Head circumference < 3rd percentile	☐	☐	
Height < 3rd percentile	☐	☐	
Weight < 3rd percentile	☐	☐	
Clinical evidence of PNH	☐	☐	
Hepatitis	☐	☐	
Other abnormalities	☐	☐	if yes, specify I_____I I_____I
Patient is twin	☐	☐	if yes: ☐ monozygotic ☐ dyzygotic

Family history in 1° relative	no	yes	unknown	
Parents are cousins	☐	☐	☐	
History of malignancies	☐	☐	☐	if yes: ☐mother; ☐father; ☐sister; ☐brother; specify I_____I

History of
Hemato-/ Immunological disease ☐ ☐ ☐ if yes, specify I_____I

Other possibly relevant diseases ☐ ☐ ☐ if yes, specify I_____I

Laboratory data

Chemistry

Hb-Electrophoresis prior to transfusion

HbA_2 I_____I (%) ☐ not done

HbF I_____I (%) ☐ not done

		Unit *(specify)*
IgA	_____	_____
IgM	_____	_____
IgG	_____	_____
Ferritin	_____	_____

Coombs test

direct ☐ neg ☐ pos

Indirect ☐ neg ☐ pos

LDH elevated ☐ no ☐ yes
(for age and laboratory range of normal)

Uric acid elevated ☐ no ☐ yes
(for age and laboratory range of normal)

HLA Type (only for RC)

|__|__|__|__| A |__|__|__|__| B |__|__|__|__| C |__|__|__|__| DRB1 |__|__|__|__| DQB1 |__|__|__|__| DPB1

|__|__|__|__| A |__|__|__|__| B |__|__|__|__| C |__|__|__|__| DRB1 |__|__|__|__| DQB1 |__|__|__|__| DPB1

Analysis to exclude Shwachman Diamond Syndrome (only for RC)

Stool elastasis ☐ normal ☐ abnormal ☐ not done if abnormal, please specify _____ _____ Unit

Trypsinogene in serum ☐ normal ☐ abnormal ☐ not done

Isoamylase in serum ☐ normal ☐ abnormal ☐ not done

Virus specific serology

		pos	neg	unknown			pos	neg	unknown
EBV-VCA	IgG	☐	☐	☐	CMV	IgG	☐	☐	☐
	IgM	☐	☐	☐		IgM	☐	☐	☐
EBV-EA	IgG	☐	☐	☐	HHV 6	IgG	☐	☐	☐
EBV-EBNA	IgG	☐	☐	☐		IgM	☐	☐	☐
Herpes Simplex	IgG	☐	☐	☐	Parvovirus B 19	IgG	☐	☐	☐
	IgM	☐	☐	☐		IgM	☐	☐	☐
HBV	IgG	☐	☐	☐	HCV	IgG	☐	☐	☐
	IgM	☐	☐	☐		IgM	☐	☐	☐
HIV		☐	☐						

Cytogenetic and Culture studies

Date of conventional cytogenetic examination (dd/mm/yy) |__|__||__|__||__|__| Please enclose copy of report

Analysis to exclude Fanconi anemia (for all primary MDS) ☐ neg ☐ pos ☐ pending ☐ not done

Studies in JMML

PTPN11 / RAS mutation	☐ not done	☐ analysed, please enclose a copy of report
	Center	I_____I
In vitro studies performed	☐ no	☐ yes ☐ not done
	Center	I_____ I

Hematological data at diagnosis

Date (dd/mm/yy) |__|__||__|__||__|__|

Peripheral blood (pre-transfusion levels)

Hb	_____	unit _____
MCV	_____	unit _____
Platelets	_____	unit _____
WBC	_____	unit _____
Ery	_____	unit _____

Bone marrow aspirate

cell content	☐ decreased	☐ normal	☐ increased
megakaryocytes	☐ decreased	☐ normal	☐ increased
	☐ none		
auer rods	☐ absent	☐ present	
Reti count	_____		

Differential count (%)	**Peripheral blood**	**Bone marrow**
Blast		
Promyelocyte		
Myelocyte		
Metamyelocyte		
Band		
Segmented		
Eosinophil		
Basophil		
Lymphocyte		
Monocyte		
Erythroblast		
	100	**100**
Name of reviewing center		

Previous Therapy

Therapy prior to diagnosis ☐ no ☐ yes

specify _____

_____

_____

Date I__I__II__I__II__I__I Signature _____