	Variable	Definition
	Date of onset	Date of first sign/symptom/abnormal CBC associated with MDS/JMML.
	Date of diagnosis	Date of first biopsy/BM aspirate (retrospectively) indicating MDS/JMML
	Diagnosis	JMML without Noonan Syndrome JMML-like disorder and Noonan Syndrome MDS • Refractory cytopenia (RC) (PB blasts <2% and BM blasts <5%) • Refractory anemia with excess blasts (RAEB) (PB blasts 2-19% or BM blasts 5-19%) • RAEB in transformation (RAEB-T) (PB or BM blasts 20-29%)
Clinical features and physical examination at diagnosis	Fatigue	yes = NCI grade ≥ 1
	Fever (>38° C)	
	Active infection	infection requiring medical attention
	Respiratory tract symptoms	
	Bleeding	yes = NCI grade ≥ 1
	Skin rash	any rash
	Spleen size	in cm below costal margin by palpation
	Liver size	in cm below costal margin by palpation
	Lymphadenopathy (>1,5cm)	any lymph node > 1,5cm
	Enlarged tonsils	Abnormally large for age
	Chloroma	
	Diabetes insipidus	Only recently developed as consequence of MDS/JMML. Exclude long-standing diabetes insipidus
	Blasts in CSF	Any blast in cytocentrifuge preparation
	Other signs or symptoms	
Associated pathology/ medical history of the patient	Xanthoma	
	Café au lait spots	café-au-lait macules over 5 mm in greatest diameter in prepubertal individuals and over 15 mm in greatest diameter in postpubertal individuals
	number	
	other symptoms of NF1	
	First degree relative with NF1	
	Previous congenital bone marrow failure disorder	e.g. Fanconi anemia, severe congential neutropenia and others
	Previous acquired bone marrow failure disorder	e.g. aplastic anemia, PNH
	Previous malignancy	
	Date of diagnosis	
	Previous chemotherapy	name of protocol, if not according protocol give chemotherapy
	Previous radiotherapy	includes radiotherapy administered according to protocol
	Mental retardation	
	Clinical evidence of PNH	yes = thrombosis or hemolysis
	Hepatitis	ALT,SGPT > 2.5 - 5.0 x ULN (WHO grade 2)
	Other abnormalities	Exclude consequences of previous therapy
Family history in 1° relatives	Parents are cousins	
	History of malignancies	
	Hemato-/Immunological diseases	
	Other possibly relevant diseases	

Laboratory data	LDH elevated for age and laboratory range of normal	
	Uric acid elevated for age and laboratory range of normal	
	HbA_2	prior to transfusion or ≥ 6 weeks after last transfusion
	HbF	prior to transfusion or ≥ 6 weeks after last transfusion
	Coombs test	positive or negative
	IgA	
	IgM	
	IgG	
	Ferritin	
	HLA type	
	stool elastasis	
	Trypsinogene in serum	
	Isoamylase in serum	
	EBV-VCA IgG/IgM	
	EBV-EA IgG/IgM	
	EBV-EBNA IgG/IgM	
	Herpes Simplex IgG/IgM	
	HBV IgG/IgM	
	HIV	
	CMV IgG/IgM	
	HHV6 IgG/IgM	
	Parvovirus B19 IgG/IgM	
	HCV IgG/IgM	
Cytogenetic and Culture studies	Date of conventional cytogenetic examination	
	Fanconi	
	PTPN11/ RAS	
	In vitro studies performed	
Hematological data at diagnosis	Hb	Date of first BM smear suspicious for MDS/JMML
	MCV	pretransfusion levels
	Platelets	pretransfusion levels
	WBC	
	Ery	pretransfusion levels
	Reti	pretransfusion levels
	Differential count (%)	Should add to 100, but because of calculations may add up 97-103.
	Cell content	
	Megakaryocytes	
	Auer rods	
	Differential count	Should add to 100, but because of calculations may add up 97-103.
	Name of reviewing center	
Previous therapy	Therapy prior to diagnosis	