

Examination interval: Every %&amp; months

Patient Name \_\_\_\_\_

Patient identification number \_\_\_\_\_

 Sex  male  female      Date of Birth (dd/mm/yy) \_\_\_\_\_

## Medical history and physical examination

Height: \_\_\_\_\_ cm

Weight: \_\_\_\_\_ cm

Schooling: \_\_\_\_\_

Grade: \_\_\_\_\_

Education: \_\_\_\_\_

	No	Yes	
Intellectual disability	<input type="checkbox"/>	<input type="checkbox"/>	
Dyslalia	<input type="checkbox"/>	<input type="checkbox"/>	
Dysmorphic features	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify: _____ _____

Xanthoma	<input type="checkbox"/>	<input type="checkbox"/>	if yes, give exact number: _____
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"Cafe au lait" spots	<input type="checkbox"/>	<input type="checkbox"/>	if yes: <input type="checkbox"/> < 10 spots give exact number ____ <input type="checkbox"/> ≥ 10
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Received anaesthesia previously	<input type="checkbox"/>	<input type="checkbox"/>	
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If yes: Complications during anaesthesia:	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
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Seizures	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
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Hepatitis/ Hepatopathy	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
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Known Bleeding disorder	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify: _____
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Bleeding complications:	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
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Spleen size below costal margin by palpation | \_\_\_\_\_ | cm

Liver size below costal margin by palpation | \_\_\_\_\_ | cm

Blood pressure: Right arm: \_\_\_\_\_ Right leg: \_\_\_\_\_ Left arm: \_\_\_\_\_ Left leg: \_\_\_\_\_

 Other signs or symptoms   if yes, specify: \_\_\_\_\_

## Therapy

### I. Observation period (no therapy)

From ( dd/mm/yy ) | \_\_\_\_\_ | until ( dd/mm/yy ) | \_\_\_\_\_ |

### II. Drug treatment:

Begin	ongoing		end	drug	dosage
	no	yes			
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____	_____
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____	_____
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____	_____
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____	_____

Remission achieved   date ( dd/mm/yy ) | \_\_\_\_\_ |

**No Yes**

II. Splenectomy   date ( dd/mm/yy ) | \_\_\_\_\_ |

### III. Stem cell transplantation:

date ( dd/mm/yy ) | \_\_\_\_\_ | (please fill in SCT form)

## Laboratory data

Date ( dd/mm/yy ) | \_\_\_\_\_ |

receives red cell transfusions regularly  no  yes

receives platelet transfusions regularly  no  yes

#### Peripheral blood

Hb \_\_\_\_\_ unit \_\_\_\_\_

MCV \_\_\_\_\_ unit \_\_\_\_\_

Platelets \_\_\_\_\_ unit \_\_\_\_\_

WBC \_\_\_\_\_ unit \_\_\_\_\_

Reti count \_\_\_\_\_

#### Bone marrow aspirate:

not done

cell content  decreased  normal  increased

megakaryocytes  decreased  normal  increased

none

auer rods  no  yes

#### Hb-Electrophoresis

HbA<sub>1</sub> | \_\_\_\_\_ | (%)  not done HbA<sub>2</sub> | \_\_\_\_\_ | (%)  not done

HbF | \_\_\_\_\_ | (%)  not done

Differential count (%)	Peripheral blood	Bone marrow
Blast		
Promyelocyte		
Myelocyte		
Metamyelocyte		
Band		
Segmented		
Eosinophil		
Basophil		
Lymphocyte		
Monocyte		
Erythroblast		
	<b>100</b>	<b>100</b>

Name of reviewing center:

**Clinical Chemistry:**

GOT/ASAT \_\_\_\_\_ unit \_\_\_\_\_ g-GT \_\_\_\_\_ unit \_\_\_\_\_ CHE \_\_\_\_\_ unit \_\_\_\_\_  
 GPT/ALAT \_\_\_\_\_ unit \_\_\_\_\_ AP \_\_\_\_\_ unit \_\_\_\_\_ Bilirubin dir \_\_\_\_\_ unit \_\_\_\_\_

**Additional Exams**

	Yes	No	
<b>Ophthalmologic exam:</b> Opticus atrophy	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify side:  _____

<b>Audiometry:</b> Hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify side:  _____
			degree:  _____

**Abdominal ultrasound incl. Doppler ultrasound:**

	No	Yes	
Pathological	<input type="checkbox"/>	<input type="checkbox"/>	
if yes, please specify:			
Splenomegaly	<input type="checkbox"/>	<input type="checkbox"/>	if yes: size below costal margin ____cm
Hepatomegaly	<input type="checkbox"/>	<input type="checkbox"/>	if yes: size below costal margin ____cm
Liver abnormality	<input type="checkbox"/>	<input type="checkbox"/>	if yes please specify: _____
Signs of vasculopathy	<input type="checkbox"/>	<input type="checkbox"/>	if yes please specify: _____
Other	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify in detail or include report: _____

		No	Yes	
<b>ECG:</b>	Pathological	<input type="checkbox"/>	<input type="checkbox"/>	if yes please specify: _____

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**Echocardiography:**

	Pathological	<input type="checkbox"/>	<input type="checkbox"/>	
	Hypertrophy	<input type="checkbox"/>	<input type="checkbox"/>	if yes please specify: _____
	Valvular pathologies	<input type="checkbox"/>	<input type="checkbox"/>	if yes please specify: _____
	Other:	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify in detail or include report: _____

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**Laboratory data:**

GOT/ASAT \_\_\_\_\_ unit \_\_\_\_\_ g-GT \_\_\_\_\_ unit \_\_\_\_\_ CHE \_\_\_\_\_ unit \_\_\_\_\_  
 GPT/ALAT \_\_\_\_\_ unit \_\_\_\_\_ AP \_\_\_\_\_ unit \_\_\_\_\_ Bilirubin dir \_\_\_\_\_ unit \_\_\_\_\_

**Additional exam every 2 years:**

		No	Yes
<b>Cranial MRI:</b>	Pathological	<input type="checkbox"/>	<input type="checkbox"/>
	if yes, please specify:		
	Leukencephalopathy	<input type="checkbox"/>	<input type="checkbox"/>
	Tumor	<input type="checkbox"/>	<input type="checkbox"/>
	Vasculitis	<input type="checkbox"/>	<input type="checkbox"/>
	Other: _____		

Date | \_\_\_\_\_ |      Signature \_\_\_\_\_