

Examination interval: Every 6 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: _____
----------	--------------------------	--------------------------	----------------------------------

"Cafe au lait" spots	<input type="checkbox"/>	<input type="checkbox"/>	if yes: <input type="checkbox"/> < 10 spots give exact number ____ <input type="checkbox"/> ≥ 10
----------------------	--------------------------	--------------------------	--

Received anaesthesia previously	<input type="checkbox"/>	<input type="checkbox"/>	
---------------------------------	--------------------------	--------------------------	--

If yes: Complications during

anaesthesia:	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
--------------	--------------------------	--------------------------	--

Seizures	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
----------	--------------------------	--------------------------	--

Hepatitis/ Hepatopathy	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
------------------------	--------------------------	--------------------------	--

Known Bleeding disorder	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify: _____
-------------------------	--------------------------	--------------------------	-------------------------------

Bleeding complications:	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please enclose medical report.
-------------------------	--------------------------	--------------------------	--

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)

## Hematological 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:

## Annual Exams

	No	Yes	
<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: _____

<b>ECG:</b>	Pathological	<input type="checkbox"/>	<input type="checkbox"/>	if yes please specify: _____
-------------	--------------	--------------------------	--------------------------	------------------------------

**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:                      No              Yes  
                                               if yes, please specify in detail or include report: \_\_\_\_\_

---

**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 \_\_\_\_\_