

Examination interval: Every 3 months

Patient Name

Patient identification number

Sex male
 female

Date of Birth (dd/mm/yy)

Medical history and physical examination

Height: cm

Weight : cm

< 1 year: Head circumference: cm

	No	Yes
Dysmorphic features	<input type="checkbox"/>	<input type="checkbox"/> if yes, please specify : <input type="text"/>

Xanthoma	<input type="checkbox"/>	<input type="checkbox"/> if yes, give exact number: <input type="text"/>
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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="text"/>
		<input type="checkbox"/> ≥ 10

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	<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: <input type="text"/>
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Bleeding complications:	<input type="checkbox"/>	<input type="checkbox"/> if yes, please enclose medical report.
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If male: Maldecensus testis	<input type="checkbox"/>	<input type="checkbox"/>
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Spleen size below costal margin by palpation cm

Liver size below costal margin by palpation cm

Blood pressure:

Right arm: Left arm:

Right leg: Left leg:

Other signs or symptoms	<input type="checkbox"/>	<input type="checkbox"/> if yes, specify: <input type="text"/>
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Motor development:

Age		No	Yes
3 months	Raises head when lying on stomach	<input type="checkbox"/>	<input type="checkbox"/>
6 months	Sits with assistance	<input type="checkbox"/>	<input type="checkbox"/>
	Head control	<input type="checkbox"/>	<input type="checkbox"/>
9 months:	Sits without support	<input type="checkbox"/>	<input type="checkbox"/>
12 months:	Pulls to stand	<input type="checkbox"/>	<input type="checkbox"/>
15 month:	Walks with assistance	<input type="checkbox"/>	<input type="checkbox"/>
18 months	Walks alone	<input type="checkbox"/>	<input type="checkbox"/>
2 years:	Walks up and downstairs holding on to support	<input type="checkbox"/>	<input type="checkbox"/>
3 years:	Jumps with both feet	<input type="checkbox"/>	<input type="checkbox"/>
	Runs with change of speed and direction	<input type="checkbox"/>	<input type="checkbox"/>
4 years	Can pedal tricycle	<input type="checkbox"/>	<input type="checkbox"/>
	Stands on one foot up to 5 sec	<input type="checkbox"/>	<input type="checkbox"/>
5 years:	Hops and stands on one foot up to 10 sec.	<input type="checkbox"/>	<input type="checkbox"/>
	Walks up and downstairs without support	<input type="checkbox"/>	<input type="checkbox"/>

Speech development

Age		No	Yes
1 year:	Speaks 1-2 words	<input type="checkbox"/>	<input type="checkbox"/>
2 years:	2-word phrases	<input type="checkbox"/>	<input type="checkbox"/>
3 years:	Uses 2-3 word phrases to talk about and ask for things	<input type="checkbox"/>	<input type="checkbox"/>
4 years:	Uses sentences with four or more words	<input type="checkbox"/>	<input type="checkbox"/>
5 years:	Speaks eloquently and uses most words correctly	<input type="checkbox"/>	<input type="checkbox"/>

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)

Haematological 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

HbA₁ | _____| (%) not done HbA₂ | _____| (%) not done

HbF | _____| (%) not done

Differential count (%)

Peripheral blood

Bone marrow

Blast

Promyelocyte

Myelocyte

Metamyelocyte

Band

Segmented

Eosinophil

Basophil

Lymphocyte

Monocyte

Erythroblast

100

100

Name of reviewing center:

Annual Exams

	No	Yes	
Ophthalmologic exam: Opticus atrophy	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify side: _____
Audiometry: Hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify side: _____ degree: _____
<1y: cranial ultrasound: Pathological	<input type="checkbox"/>	<input type="checkbox"/>	if yes, please specify in detail or enclose report:

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 enclose report: _____

ECG:	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 enclose report: _____

Additional laboratory data:

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

Date | _____ |

Signature _____