

## Prospective study registry of neuroblastoma patients with SCI

## REGISTRATION

## INSTITUTION

(Please print)

Hospital name \_\_\_\_\_

City, country \_\_\_\_\_

Telephone \_\_\_\_\_ Fax \_\_\_\_\_

E-mail \_\_\_\_\_

Registering Physician \_\_\_\_\_

## PATIENT FEATURES

NB Trial number\* |\_\_|\_\_|\_\_|\_\_|\_\_|

Birthdate |\_\_|\_\_|\_\_|\_\_|\_\_| mm/yyyy

(\*please contact the German Neuroblastoma Trial office for trial number assignment, if not known (+49-221-478-6853))

Gender

☐ Male☐ Female

Pre-existing neurologic abnormalities (e.g. spina bifida, Duchenne)

☐ NO☐ YES^

Other congenital abnormalities (e.g. cleft palate, heart disease)

☐ NO☐ YES^

^If yes, specify \_\_\_\_\_

## ELIGIBILITY CRITERIA

Imaging of spinal canal involvement

☐ NO^☐ YES

Diagnosis of peripheral neuroblastic tumour

☐ NO^☐ YES

if NO, specify \_\_\_\_\_

Age under 18 years

☐ NO^☐ YES

No previous chemotherapy in the last 6 months, except steroids

☐ NO^☐ YES

Written informed parent / patient consent to enrolment into the study

☐ NO^☐ YES

^: Send only this CRF to the National Coordinator. The patient is not eligible for the study.

If all "yes" are checked, go to CRF1b

PHYSICIAN SIGNATURE \_\_\_\_\_

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

**To be sent by fax or e-mail to your National Coordinator**(for Germany: Fax +49-221-478-6851, email: Neuroblastomstudie@uk-koeln.de)

Do not complete; assigned by the NB-SCI Centre

Unique Patient Number NB-SCI |\_\_|\_\_|\_\_|\_\_|\_\_|

## Prospective study registry of neuroblastoma patients with SCI

**WORK-UP AT DIAGNOSIS**

Unique Patient Number NB-SCI |\_\_|\_\_|\_\_|-|\_\_|\_\_|\_\_|

**Primary tumour site(s)** ☐ Cervical ☐ Thoraco-abdominal ☐ Abdomino-pelvic  
☐ Cervico-thoracic ☐ Abdominal adrenal ☐ Pelvic  
☐ Thoracic ☐ Abdominal other ☐ Not identified

**Diagnostic surgery/biopsy** ☐ NO ☐ YES *if yes, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy*

**if yes, on** ☐ Intraspinal tumour ☐ Extrapinal tumour ☐ Bone marrow

**Histology (according INPC)**

➤ *Neuroblastoma* ☐ Undifferentiated ☐ Poorly differentiated ☐ Differentiating ☐ NOS  
➤ *Ganglioneuroblastoma* ☐ Intermixed ☐ Nodular ☐ NOS  
➤ *Ganglioneuroma* ☐ Maturing ☐ Mature  
➤ *Other* ☐ specify \_\_\_\_\_

**Biology**

**MYCN** ☐ Unknown ☐ Amplified ☐ Normal

**Chromosomal aberrations evaluated?** ☐ NO ☐ YES, with CGH ☐ YES, with other \_\_\_\_\_

**Chromosomal aberrations?** ☐ NO ☐ YES

**If yes, type** ☐ Numerical ☐ Segmental

Specify \_\_\_\_\_

**INSS Stage** ☐ 1 ☐ 2A ☐ 2B ☐ 3 ☐ 4 ☐ 4S

**INRG Stage** ☐ L1 ☐ L2 ☐ M ☐ MS

**Treatment protocol/arm** \_\_\_\_\_

☐ Treatment for peripheral neuroblastic tumour at onset

☐ Treatment for peripheral neuroblastic tumour at relapse

## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|

Spinal imaging\* ☐ MRI, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy ☐ CT, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy*\* Send reports and imaging ( MRI and/or CT, preferably on CD) to your National Coordinator (address on page 4-6 of the protocol)*

Intraspinal level of tumour invasion

<input type="checkbox"/> Cervical	}	Vertebra number	
<input type="checkbox"/> Cervico-thoracic		From	To
<input type="checkbox"/> Thoracic			
<input type="checkbox"/> Thoraco-abdominal		__ __ __ __	__ __ __ __
<input type="checkbox"/> Abdominal			
<input type="checkbox"/> Abdomino-pelvic			
<input type="checkbox"/> Pelvic			

*In case of double primary*

<input type="checkbox"/> Cervical	}	Vertebra number	
<input type="checkbox"/> Cervico-thoracic		From	To
<input type="checkbox"/> Thoracic			
<input type="checkbox"/> Thoraco-abdominal		__ __ __ __	__ __ __ __
<input type="checkbox"/> Abdominal			
<input type="checkbox"/> Abdomino-pelvic			
<input type="checkbox"/> Pelvic			

Degree of spinal canal invasion ☐ <33% ☐ 33-66% ☐ >66%*In case of double primary* ☐ <33% ☐ 33-66% ☐ >66%Spinal cord T2 hyperintensity at MRI ☐ NO ☐ YES ☐ MRI not doneSomatosensory evoked potentials at diagnosis ☐ Unknown ☐ Not done ☐ Done*(if done, check the corresponding box as appropriate)**if done, date* |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy

Upper limbs	<input type="checkbox"/> Normal	<input type="checkbox"/> Abnormal	<input type="checkbox"/> Not performed
Lower limbs	<input type="checkbox"/> Normal	<input type="checkbox"/> Abnormal	<input type="checkbox"/> Not performed

## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|\_|-|\_\_|\_\_|\_|

## SCI – ORIENTED CLINICAL EVALUATION AT DIAGNOSIS

Age 0 – 35 months

Attained age (months) |\_\_|\_\_|

Symptom(s) of spinal canal involvement

☐ NO☐ YES

Date of first symptom(s) |\_\_|\_\_|\_|\_|\_|\_| dd/mm/yy specify symptom(s) \_\_\_\_\_

Date of first medical visit |\_\_|\_\_|\_|\_|\_|\_| dd/mm/yy \_\_\_\_\_

Date of SCI imaging |\_\_|\_\_|\_|\_|\_|\_| dd/mm/yy \_\_\_\_\_

	AT FIRST MEDICAL VISIT*				AT SCI IMAGING*			
<b>Psychomotor competence</b> <i>(month at which the milestone is physiologically achieved; if actual age &lt; to the specific milestone, mark NA)</i>	N	A	NE	NA	N	A	NE	NA
Suction (0 mos)								
Social smile/visual contact (2mos)								
Head control (3 mos)								
Sitting (8 mos)								
Standing (11 mos)								
Grasping (8 mos)								
Walking (12 mos)								
<b>Signs of neurovegetative dysfunction</b>	NO	YES	NE	NA	NO	YES	NE	NA
Pallor								
Marbled skin								
Hiccup ( <i>more than physiologic for age</i> )								
Regurgitation ( <i>more than physiologic for age</i> )								
Tremor								
Clonus								
<b>Other, specify</b>								

Symptoms <i>(according to FLACC, CTCAE and ASIA scales, see Appendix 2)</i>		AT FIRST MEDICAL VISIT	AT SCI IMAGING
		SCORE	SCORE
General	Upper motor deficit (ASIA)	__	__
	Lower motor deficit (ASIA)	__	__
	Pain (FLACC)	__ __	__ __
	Dyspnea (CTCAE)	__	__
	Paresthesia (CTCAE)	__	__
Bowel function ( <i>if age &gt;24 months</i> )*		__ __	__ __
Bladder function ( <i>if age &gt;24 months</i> )*		__ __	__ __
Spine	Joint range of motion decreased, cervical spine (CTCAE)	__	__
	Joint range of motion decreased, lumbar spine (CTCAE)	__	__
	Scoliosis (CTCAE)	__	__
	Kyphosis (CTCAE)	__	__
	Lordosis (CTCAE)	__	__
Other, specify		__	__

\* N, normal; A, abnormal; NE, not evaluated; NA, not assessable

## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|-|\_\_|\_\_|\_\_|

## SCI – ORIENTED CLINICAL EVALUATION AT DIAGNOSIS

Age ≥ 36 months

Attained age (months) |\_\_|\_\_|\_\_|

Symptom(s) of spinal canal involvement

☐ NO☐ YES

Date of first symptom(s) |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy specify symptom(s) \_\_\_\_\_

Date of first medical visit |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy \_\_\_\_\_

Date of SCI imaging |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy \_\_\_\_\_

		AT FIRST MEDICAL VISIT	AT SCI IMAGING
Symptoms (according to the, CTCAE and ASIA scales, see Appendix 2)		Score	Score
General	Upper motor deficit (ASIA)	__	__
	Lower motor deficit (ASIA)	__	__
	Pain (CTCAE)	__	__
	Dyspnea (CTCAE)	__	__
	Paresthesia (CTCAE)	__	__
Bowel	Fecal incontinence (CTCAE)	__	__
	Constipation (CTCAE)	__	__
Bladder	Urinary incontinence (CTCAE)	__	__
	Urinary retention (CTCAE)	__	__
Spine	Joint range of motion decreased, Cervical spine (CTCAE)	__	__
	Joint range of motion decreased, Lumbar spine (CTCAE)	__	__
	Scoliosis (CTCAE)	__	__
	Kyphosis (CTCAE)	__	__
	Lordosis (CTCAE)	__	__
	Other, specify	__	__

Comments \_\_\_\_\_

PHYSICIAN SIGNATURE \_\_\_\_\_

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

## Prospective study registry of neuroblastoma patients with SCI

## CLINICAL RESPONSE TO THERAPY FOR SCI

Unique Patient Number NB-SCI |\_\_|\_\_|\_|\_|\_|\_|\_|

## TREATMENT DECISION WITHIN 2 MONTHS FROM DIAGNOSIS OF SCI

**Surgery on extraspinal tumour**    ☐ NO    ☐ YES    *If yes, date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy*  
**Neurosurgery**    ☐ NO    ☐ YES    *If yes, date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy*  
**Chemotherapy**    ☐ NO    ☐ YES    *If yes, starting date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy*  
**Radiotherapy**    ☐ NO    ☐ YES    *If yes, starting date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy*  
**Wait-and-see**    ☐ NO    ☐ YES    *If yes, starting date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy*

	AGE 0-35 MONTHS	AGE ≥ 36 MONTHS
Time from first therapeutic decision (Including wait-and-see)	SCORE	SCORE
	MOTOR DEFICIT (ASIA)	MOTOR DEFICIT (ASIA)
within 72 hours	__	__
between 72 hours– 1 week	__	__
between 1 week – 2 weeks	__	__
between 2 weeks – 4 weeks	__	__
between 1 month – 2 months	__	__
	PAIN (FLACC)	PAIN (CTCAE)
within 72 hours	__	__
between 72 hours– 1 week	__	__
between 1 week – 2 weeks	__	__
between 2 weeks – 4 weeks	__	__
between 1 month – 2 months	__	__
	BLADDER DYSFUNCTION^ (if age >24 months)	BLADDER DYSFUNCTION (CTCAE)
within 72 hours	__	__
between 72 hours– 1 week	__	__
between 1 week – 2 weeks	__	__
between 2 weeks – 4 weeks	__	__
between 1 month – 2 months	__	__
	BOWEL DYSFUNCTION^ (if age >24 months)	BOWEL DYSFUNCTION (CTCAE)
within 72 hours	__	__
between 72 hours– 1 week	__	__
between 1 week – 2 weeks	__	__
between 2 weeks – 4 weeks	__	__
between 1 month – 2 months	__	__

^ N, normal; A, abnormal; NE, not evaluated; NA, not assessable

## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|-|\_\_|\_\_|\_\_|

## Somatosensory evoked potentials after treatment for SCI

☐ Unknown ☐ Not done ☐ Done

(if done, check the corresponding box as appropriate)

if done, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy

Upper limbs

☐ Normal☐ Abnormal☐ Not performed

Lower limbs

☐ Normal☐ Abnormal☐ Not performed

## Comments

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PHYSICIAN SIGNATURE \_\_\_\_\_

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

## Prospective study registry of neuroblastoma patients with SCI

## TREATMENT SUMMARY

Unique Patient Number NB-SCI |\_\_|\_\_|-|\_\_|\_\_|\_\_|

Treatment protocol/arm \_\_\_\_\_

- ☐ Treatment for peripheral neuroblastic tumour at onset
- ☐ Treatment for peripheral neuroblastic tumour at relapse

## IMMEDIATE NEUROSURGERY

Immediate neurosurgery ☐ Unknown ☐ NO ☐ YES

If yes, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy

## Indications

- Progressive deficit ☐ Unknown ☐ NO ☐ YES
- Size of intraspinal tumour ☐ Unknown ☐ NO ☐ YES
- Severity of deficit ☐ Unknown ☐ NO ☐ YES
- Other reasons ☐ YES, specify \_\_\_\_\_

Type of surgery ☐ Unknown ☐ Laminectomy ☐ Laminotomy ☐ other \_\_\_\_\_

Level of surgical resection (vertebra-number) From |\_\_|\_\_|-|\_\_|\_\_| To |\_\_|\_\_|-|\_\_|\_\_|

Type of procedure ☐ Unknown ☐ Open surgery ☐ Minimally invasive

Resection of intraspinal component ☐ Complete

☐ With minimal residue (tumour residue <5% or < 5 ml)

☐ Incomplete (tumour residue >5% or > 5 ml)

☐ Unknown

Root sacrifice ☐ Unknown ☐ NO ☐ YESBlood loss (1 unit = 80 cc/kg) ☐ Unknown ☐ <1 ☐ 1-2 ☐ > 2

Please, send neurosurgical report to your National Coordinator (address on page 4-6 of the protocol)

## SURGERY ON EXTRASPINAL TUMOUR AT DIAGNOSIS

Surgery on extraspinal tumour at diagnosis ☐ Unknown ☐ NO ☐ YES

If yes, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy

Tumour resection ☐ Complete ☐ With minimal residue ☐ Incomplete ☐ Biopsy ☐ Unknown

Please, send surgical report to your National Coordinator (address on page 4-6 of the protocol)



## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|-|\_\_|\_\_|\_\_|

## LATE NEUROSURGERY

Late neurosurgery ☐ Unknown ☐ NO ☐ YES

If yes, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy

## Indications

Removal of residual intraspinal tumour ☐ Unknown ☐ NO ☐ YESNew or progressive deficit ☐ Unknown ☐ NO ☐ YESOther reasons ☐ YES, specify \_\_\_\_\_Type of surgery ☐ Unknown ☐ Laminectomy ☐ Laminotomy ☐ other \_\_\_\_\_

Level of surgical resection (vertebra-number) From |\_\_|\_\_|-|\_\_|\_\_| To |\_\_|\_\_|-|\_\_|\_\_|

Type of procedure ☐ Unknown ☐ Open surgery ☐ Minimally invasive

Resection of intraspinal component ☐ Complete

☐ With minimal residue (tumour residue <5% or < 5 ml)

☐ Incomplete (tumour residue >5% or > 5 ml)

☐ Unknown

Root sacrifice ☐ Unknown ☐ NO ☐ YESBlood loss (1 unit = 80 cc/kg) ☐ Unknown ☐ <1 ☐ 1-2 ☐ > 2

Please, send neurosurgical report to your National Coordinator (address on page 4-6 of the protocol)

## DELAYED SURGERY ON EXTRASPINAL TUMOUR

Delayed surgery on extraspinal tumour ☐ Unknown ☐ NO ☐ YES

If yes, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy

Tumour resection ☐ Complete ☐ With minimal residue ☐ Incomplete ☐ Biopsy ☐ Unknown

Please, send surgical report to your National Coordinator (address on page 4-6 of the protocol)

## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|\_|\_|\_|\_|\_|

## PHARMACOLOGICAL TREATMENT

Chemotherapy ☐ Unknown ☐ NO ☐ YES

If yes, date of first course |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

date of last course (including high-doses) |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

Steroid ☐ Unknown ☐ NO ☐ YES If yes, date of the start |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yyImmunotherapy ☐ Unknown ☐ NO ☐ YES

## RADIATION THERAPY

Radiation therapy ☐ Unknown ☐ NO ☐ YES

If yes, date of the start |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

date of the end |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

Irradiated area (vertebra-number) From |\_\_|\_|\_|\_|\_| To |\_\_|\_|\_|\_|\_| Dose Gy |\_\_|\_|\_|

In case of double primary  
(vertebra-number) From |\_\_|\_|\_|\_|\_| To |\_\_|\_|\_|\_|\_| Dose Gy |\_\_|\_|\_|PROGRESSION OR RELAPSE BEFORE 1<sup>ST</sup> ELECTIVE END OF THERAPIESProgression or relapse ☐ Unknown ☐ NO ☐ YES

If yes, date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

## BEST RESPONSE OF INTRASPINAL TUMOUR (SCI) AT NEURO-IMAGING

Best response ☐ Unknown ☐ Not available ☐ Available

If available, date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

## Type

☐ Complete☐ None☐ Sub-total (66-99%)☐ Progression☐ Partial (33-65%)☐ Unknown☐ Minimum (1-32%)

\* Send reports and imaging ( MRI and/or CT, preferably on CD) to your National Coordinator (address on page 4-6 of the protocol)

## Prospective study registry of neuroblastoma patients with SCI

## OVERALL TUMOUR RESPONSE

**Overall response** ☐ Unknown ☐ Not available ☐ Available

*If available, date |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy*

**Best tumour response**☐ CR☐ NR☐ VGPR☐ PD☐ PR☐ Unknown☐ MR

**Comments** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PHYSICIAN SIGNATURE** \_\_\_\_\_

**Date** |\_\_|\_\_|\_\_|\_\_|\_\_|\_\_| dd/mm/yy

## Prospective study registry of neuroblastoma patients with SCI

**FOLLOW-UP AGE 0 – 35 MONTHS****Attained age (months)** |\_\_|\_\_|**Unique Patient Number NB-SCI** |\_\_|\_\_|\_|\_|\_|\_|\_|**Date of follow-up visit**

|\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

**Time from first therapeutic decision**☐ 6 m☐ 1 yr☐ 2 yr

SYMPTOMS (evaluated according to the FLACC, CTCAE and ASIA scales, see Appendix 2)		Score
General	Upper motor deficit (ASIA)	__
	Lower motor deficit (ASIA)	__
	Is assistance is needed, specify (1) Walker (2) Frame (3) Wheelchair (4) Other, specify	__
	Pain Score (FLACC)	__ __
	Dyspnea (CTCAE)	__
	Paresthesia (CTCAE)	__
Bowel	Bowel function ( <b>N</b> , normal; <b>A</b> , abnormal; <b>NE</b> , not evaluated; <b>NA</b> , not assessable)	__ _ _
	Describe abnormal bowel function (1) constipation without treatment (3) constipation requiring manual evacuation (2) constipation with treatment (4) incontinence	__
Bladder	Bladder function, ( <b>N</b> , normal; <b>A</b> , abnormal; <b>NE</b> , not evaluated; <b>NA</b> , not assessable) Urodynamic report if abnormal	__ _ _
	Need for catheterisation (1) No (2) yes (3) unknown	__
	Recurrent urinary tract infections (1) No (2) yes without preventive treatment (3) yes with preventive treatment (4) unknown	__
Spine	Joint range of motion decreased, cervical spine (CTCAE)	__
	Joint range of motion decreased, lumbar spine (CTCAE)	__
	Scoliosis (CTCAE)	__
	Kyphosis (CTCAE)	__
	Lordosis (CTCAE)	__
	Other, specify	__

**PD/Relapse after 1<sup>st</sup> elective end of therapies** ☐ NO ☐ YES if yes, date |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy**Overall disease status** ☐ CR ☐ Alive with stable disease ☐ Alive with progressive disease ☐ Dead**Status of the intraspinal tumour** ☐ No tumour ☐ Residual tumour of canal invasion ☐ <33% ☐ 33-66% ☐ >66%  
☐ MRI not performed**PHYSICIAN SIGNATURE** \_\_\_\_\_**Date** |\_\_|\_\_|\_|\_|\_|\_|\_| dd/mm/yy

## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|-|\_\_|\_\_|\_\_|

**Comments** \_\_\_\_\_

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PHYSICIAN SIGNATURE \_\_\_\_\_

**Date** |\_\_|\_|\_|\_|\_|\_|\_| *dd/mm/yy*

## Prospective study registry of neuroblastoma patients with SCI

**FOLLOW-UP AGE  $\geq$  36 MONTHS**      Attained age (months) | | |

Unique Patient Number NB-SCI			-			
------------------------------	--	--	---	--	--	--

**Date of follow-up visit**

| | | | | | dd/mm/yy

### Time from first therapeutic decision

☐ 6 m

☐ 1 vr

 $\square \quad 2 \text{ vr}$ ☐ 3 yr☐ 4 vr☐ 5 yr

☐ 10 vr

SYMPTOMS (evaluated according to the CTCAE and ASIA scales, see Appendix 2)		Score
General	Upper motor deficit (ASIA)	_
	Lower motor deficit (ASIA)	_
	Is assistance is needed, specify (1) Walker (2) Frame (3) Wheelchair (4) Other, specify	_
	Pain (CTCAE)	_
	Dyspnea (CTCAE)	_
	Paresthesia (CTCAE)	_
Bowel	Fecal incontinence (CTCAE)	_
	Constipation (CTCAE)	_
Bladder	Urinary incontinence (CTCAE)	_
	Urinary retention (CTCAE)	_
	Recurrent urinary tract infections (1) No (2) yes without preventive treatment (3) yes with preventive treatment (4) unknown	_
Spine	Joint range of motion decreased, cervical spine (CTCAE)	_
	Joint range of motion decreased, lumbar spine (CTCAE)	_
	Scoliosis (CTCAE)	_
	Kyphosis (CTCAE)	_
	Lordosis (CTCAE)	_
	Other, specify	_

**PD/Relapse after 1<sup>st</sup> elective end of therapies**    ☐ NO    ☐ YES    *if yes, date* |    |    |    |    |    *dd/mm/yy*

**Overall disease status**   ☐ CR   ☐ Alive with stable disease   ☐ Alive with progressive disease   ☐ Dead

**Status of the intraspinal tumour** ☐ No tumour ☐ Residual tumour of canal invasion ☐ <33% ☐ 33-66% ☐ >66%  
☐ MRI not performed

PHYSICIAN SIGNATURE \_\_\_\_\_

Date | | | | | | dd/mm/yy

## Prospective study registry of neuroblastoma patients with SCI

Unique Patient Number NB-SCI |\_\_|\_\_|-|\_\_|\_\_|\_\_|

[illegible]

**PHYSICIAN SIGNATURE** \_\_\_\_\_

**Date** |\_\_| |\_\_| |\_\_| |\_\_| |\_\_| |\_\_| *dd/mm/yy*