Svenska barncancerregistret – VCTB
Treatment - formulär

Report date: | 2 | 0 |___|___|___|___|___|___|
Forename:
Surname:
Date of Birth: | 2 | 0 |___|___|___|___|___|___| - |___|___|___|___|
Gender: ☐ Female ☐ Male
Home adress:
City:
Country:

Treatment first line

Intention

☐ Active tumor treatment ☐ Palliative tumor treatment ☐ Active expectancy

If Palliative tumor treatment, please specify:

_____

Comment:

_____
_____
_____
_____

Protocol/Study

Included (registered) in clinical treatment study

☐ Yes ☐ No

If Included (registered) in clinical treatment study
Is Yes, please fill in below

Specify treatment (One option)

- ☐ Clinical trial with option to randomize
- ☐ Clinical trial without option to randomize (observational study) but with registration

Comment treatment

_____

Name (one option)

- ☐ SIOP PNET 5 MB 2015
- ☐ HIT-MED guidance 2017
- ☐ BIOMEDE 2018
- ☐ SIOP LGG 2004
- ☐ SIOP HRMB
- ☐ SIOP Ependymoma II 2017
- ☐ SIOP CNS GCT II 2015
- ☐ EU Rhab 2016
- ☐ Other

If SIOP PNET 5 MB 2015 has been choosen, please specify (one option)

- ☐ SIOP PNET 5 MB 2015 Standardrisk (SR)
- ☐ SIOP PNET 5 MB 2015 Low risk (LR)
- ☐ SIOP PNET 5 MB 2015 WNT-HR
- ☐ SIOP PNET 5 MB 2015 SHH TP53
- ☐ SIOP PNET 5 MB 2015 Registry

If HIT-MED guidance 2017 has been choosen, please specify (one option)

- ☐ 4.1. SKK chemotherapy
- ☐ 4.2. Intensified Induction chemotherapy with response-adjusted consolidation
- ☐ Other

If Other, please specify

_____

If SIOP Ependymoma II 2017 has been choosen, please specify (one option)

- ☐ SIOP Ependymoma II Stratum I
- ☐ SIOP Ependymoma II Stratum II
- ☐ SIOP Ependymoma II Stratum III
- ☐ SIOP Ependymoma II Observational study

If Other has been choosen, please specify

_____

If Included (registered) in clinical treatment study
Is No, please fill in below:

Reason for not participating

- ☐ Clinical treatment trial NOT available
- ☐ Clinical trial available, but patient not included

If Clinical trial available, but patient not included, please fill in below:

Reason for non-inclusion in trial

- ☐ Patient related reason
- ☐ Health care related reason
- ☐ Other reason

If Other reason, please specify

_____

Specify treatment (One option)

- ☐ Further treatment not indicated
- ☐ Treatment protocol without registration
- ☐ No protocol, treatment without program/individual treatment
- ☐ Compassionate use program
- ☐ Other

If Other, please specify below

_____

Comment treatment

_____

Comment (specify e.g. riskgroup, protocol arm/stratum, randomization arm etc.)

_____

Registration in other studies

_____

Comment (specify e.g. riskgroup, protocol arm/stratum, randomization arm etc.) _____ **Registration in other studies** _____	

Primary tumor surgery

Primary tumor surgery

☐ Yes ☐ No ☐ Data missing

If Yes, please fill in below

Date of tumor surgery

| 2 | 0 |___|___|___|___|___|___|

Hospital (One option)

- ☐ Stockholm
- ☐ Uppsala
- ☐ Göteborg
- ☐ Umeå
- ☐ Lund
- ☐ Linköping
- ☐ Other

Preoperative hydrocephalus (One option)

☐ No ☐ Slight (enlarged ventricles) ☐ Moderate (periventricular edema) ☐ Servere (compressed sulci at the vertex)

☐ Data missing

Result of surgery according to surgeon (One option)

☐ Total resection ☐ Subtotal resection ☐ Partial resection ☐ Biopsy ☐ Data missing

Result of surgery according to first postoperative MRI (One option)

☐ Total resection ☐ Subtotal resection ☐ Partial resection ☐ Biopsy ☐ Data missing

Surgical treatment of metastases at diagnosis

☐ Yes ☐ No ☐ Data missing

If yes at Surgical treatment of metastases at diagnosis, please specify

_____

Result of surgery according to first postoperative MRI (One option)

☐ Total resection ☐ Subtotal resection ☐ Partial resection ☐ Biopsy ☐ Data missing

Secondary tumor surgery

<u>Only fills in if Primary tumor surgery is Yes</u>

Second tumor surgery

☐ Yes ☐ No ☐ Data missing

Date of tumor surgery

|2|0|__|__|__|__|__|__|

Result

☐ Total resection ☐ Subtotal resection ☐ Partial resection ☐ Biopsy ☐ Data missing

Surgery comments:

_____
_____
_____
_____

Surgical complications

Only fills in if Primary tumor surgery is Yes

Cerebellar mutism syndrome

☐ Yes ☐ No ☐ Data missing

Intracranial haemorrhage requiring surgery

☐ Yes ☐ No ☐ Data missing

Hydrocephalus requiring surgery

☐ Yes ☐ No ☐ Data missing

CNS infection

☐ Yes ☐ No ☐ Data missing

Stroke

☐ Yes ☐ No ☐ Data missing

If Yes at Stroke, please fill in verified by CT/MRI

☐ Yes ☐ No ☐ Data missing

Comment:

_____
_____
_____
_____

Other surgical complications of grade 3-4

☐ Yes ☐ No ☐ Data missing

Comment:

_____
_____
_____
_____

Preoperative complications

Only fills in if Primary tumor surgery is Yes

Vision for age

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing ☐ Not applicable

Squint

☐ Yes ☐ No ☐ Data missing

Facial motor function

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Swallowing

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Airway/breathing

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Arm coordination (ataxia)

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Truncal stability (ataxia)

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Limb weakness/ paresis

☐ Yes ☐ No ☐ Data missing

Difficulties standing

☐ Yes ☐ No ☐ Not applicable ☐ Data missing

Difficulties walking

☐ Yes ☐ No ☐ Not applicable ☐ Data missing

Seizures

☐ Yes ☐ No ☐ Data missing

Postoperative complications (within 30 days from surgery)

Only fills in if Primary tumor surgery is Yes

Vision for age

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing ☐ Not applicable

Squint

☐ Yes ☐ No ☐ Data missing

Facial motor function

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Swallowing

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Airway/breathing

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Arm coordination (ataxia)

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Truncal stability (ataxia)

☐ Normal/no abnormality recorded ☐ Abnormal/impaired ☐ Data missing

Limb weakness/ paresis

☐ Yes ☐ No ☐ Data missing

Difficulties standing

☐ Yes ☐ No ☐ Data missing

Difficulties walking

☐ Yes ☐ No ☐ Data missing

Seizures

☐ Yes ☐ No ☐ Data missing

Comment:

_____
_____
_____
_____

Radiotherapy

Radiotherapy

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Start RT

|2|0|___|___|___|___|___|___|

End RT

|2|0|___|___|___|___|___|___|

RT technique

- ☐ Photons
- ☐ Protons
- ☐ Stereotaxi

If Stereotaxi has chosen, please fill in below

_____

Stereotaxi, method

☐ Linear acceleration ☐ Gamma knife ☐ Other technique

If Other technique, please specify other

_____

RT total dose (Gy) to primary tumor

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy) to craniospinal axis

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy) to ventricles focal

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy) to metastasis

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy), Other

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Specify location: _____ ☐ Data missing

Gy: _____ ☐ Data missing

Chemotherapy

Chemotherapy

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Start Chemotherapy

| 2 | 0 |___|___|___|___|___|___|

Stop Chemotherapy

| 2 | 0 |___|___|___|___|___|___|

Drugs (several options)

- ☐ Cisplatin
- ☐ Carboplatin
- ☐ Etoposide
- ☐ Cyclofosfamide
- ☐ Ifosfamide
- ☐ Methotrexate
- ☐ Vincristine
- ☐ Vinblastine
- ☐ CCNU
- ☐ Temozolomide
- ☐ Other

If Other, please specify

_____

High dose chemotherapy with stem cell rescue (HDSCR)

☐ Yes ☐ No ☐ Data missing

First HDSCR

| 2 | 0 |___|___|___|___|___|___|

Second HDSCR

| 2 | 0 |___|___|___|___|___|___|

Comment:

_____
_____
_____
_____

Other therapy

Intrathecal treatment

☐ Yes ☐ No ☐ Data missing

If Yes, please specify

_____

Targeted therapy

☐ Yes ☐ No ☐ Data missing

If Yes, please specify

_____

Immunotherapy

☐ Yes ☐ No ☐ Data missing

If Yes, please specify

_____

Other therapy

☐ Yes ☐ No ☐ Data missing

If Yes, please specify

_____

Comment:

_____
_____
_____
_____

Treatment response

Response to first line treatment according to MRI (One option)

- ☐ Complete response (CR)
- ☐ Partial response (PR)
- ☐ Stable disease (SD
- ☐ Progressive disease (PD)
- ☐ Death during first line treatment

First line therapy stopped

|2|0|___|___|___|___|___|___|

First line therapy stopped due to (One option)

- ☐ Planned treatment completed
- ☐ Tumor progression/relapse
- ☐ Side effects
- ☐ Death
- ☐ Other cause

If Other cause, please specify

_____

Comment:

_____
_____
_____
_____

Second line treatment

Second line treatment

☐ Yes ☐ No ☐ Data missing

If Yes, please fill in below

Start of second line treatment

| 2 | 0 |___|___|___|___|___|___|

End of second line treatment

| 2 | 0 |___|___|___|___|___|___|

Second line treatment started due to

☐ Relapse/progression ☐ Toxicity ☐ Other cause

If Other cause, please specify

_____

Access to clinical study for second line treatment (One option)

- ☐ Clinical trial with option to randomize
- ☐ Clinical trial without option to randomize (observational study) but with registration
- ☐ Further treatment not indicated
- ☐ Treatment protocol without registration
- ☐ No protocol, treatment without program/individual treatment
- ☐ Compassionate use program
- ☐ Other

Comment:

_____
_____
_____
_____

Surgery

<u>Only fills in if Second line treatment is Yes</u>

Second line surgery

☐ Yes ☐ No ☐ Data missing

If Yes, please fill in below

Surgery date

| 2 | 0 |___|___|___|___|___|___|

Comment:

_____
_____
_____
_____

Radiotherapy

Only fills in if Second line treatment is Yes

Radiotherapy

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Start RT

| 2 | 0 |___|___|___|___|___|___|

End RT

| 2 | 0 |___|___|___|___|___|___|

RT technique (Several options)

- ☐ Photons
- ☐ Protons
- ☐ Stereotaxi

RT total dose (Gy) to primary tumor

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy) to craniospinal axis

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy) to ventricles focal

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy) to metastasis

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Gy: _____ ☐ Data missing

Fraction, Gy: _____ ☐ Data missing

RT total dose (Gy), Other

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Specify location: _____ ☐ Data missing

Gy: _____ ☐ Data missing

Comment:

_____
_____
_____

Chemotherapy

Only fills in if Second line treatment is Yes

Second line chemotherapy

☐ Yes ☐ No ☐ Data missing

If yes, please fill in below

Drugs (several options)

- ☐ Cisplatin
- ☐ Carboplatin
- ☐ Etoposide
- ☐ Cyclofosfamide
- ☐ Ifosfamide
- ☐ Methotrexate
- ☐ Vincristine
- ☐ Vinblastine
- ☐ CCNU
- ☐ Temozolomide
- ☐ Other

HDSCR

☐ Yes ☐ No ☐ Data missing

Second line targeted therapy

☐ Yes ☐ No ☐ Data missing

If Yes, please specify

_____

Second line immunotherapy

☐ Yes ☐ No ☐ Data missing

If Yes, please specify

_____

Second line other therapy

☐ Yes ☐ No ☐ Data missing

If Yes, please specify

_____

Comment:

_____
_____
_____
_____

Response second line treatment

Only fills in if Second line treatment is Yes

Response to second line treatment

- ☐ Complete response (CR)
- ☐ Partial response (PR)
- ☐ Stable disease (SD)
- ☐ Progressive disease (PD)
- ☐ Death
- ☐ Too soon for evaluation
- ☐ Data missing

Comment:

_____
_____
_____
_____