

HELP	STEP 1. SETTINGS	STEP 2. ELEMENTS	STEP 3. OVERVIEW
STEP 4. PREVIEW	STEP 5. ADDITIONAL OPTIONS	STEP 6. PUBLISH	

STEP 4. Preview

Tip: Click on a text to edit.

Add an element

Seite: 1

Fortschritt_Basis	Fortgang	kopieren	anpassen
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[Fortgangsbalken]

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TREATMENT_OF_PROGRESSIVE_OPG_<1_yr	Überschrift	kopieren	anpassen
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Treatment of Progressive Optic Pathway Glioma in Infants

Einleitung_[KLICKEN,_UM_ ANZUPASSEN]	Zwischentext	kopieren	anpassen
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Sporadic infant chiasmatic / hypothalamic glioma (ICHG) has to be considered as a chronic disease and almost invariably will necessitate subsequent treatment episodes at progression (i.e. second-line or third-line treatment).

The dismal prognosis of ICHG made us design a specific questionnaire for this disease. It shall help to characterise current treatment decisions for progressive infant chiasmatic / hypothalamic glioma (ICHG), i.e. children diagnosed during the first year of life.

All questions below therefore ONLY concern INFANTS with chiasmatic / hypothalamic glioma (i.e. DIAGNOSED during the first year of life).

authors	Zwischentext	kopieren	anpassen
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This survey has been initiated by Amedeo A. Azizi and A.Y.N. Schouten - van Meeteren on behalf of the

SIOP-E Low Grade Glioma working group.

Neue Seite | kopieren | anpassen

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Seite: 2 | PAGE_2

previous

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LIST_of_QUESTIONS | Static Text | copy | adjust

QUESTIONS to following topics will be asked.

- Progression DURING Carboplatin / VINCRISTIN
- Progression DURING Carboplatin / VINBLASTIN
- Progression AFTER Therapy
- LENGTH of 1st line treatment
- BEVACIZUMAB
- RADIATION THERAPY
- GENERAL INFORMATIONS

Answering the questionnaire will take 10-15 minutes.
Thank you for your time.

New page | copy | adjust

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Page: 3 | PROGRESSION_DURING_Carbo/VCR

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33%

reminder_patient_cohort | Title | copy | adjust

All questions below ONLY concern children with Chiasmatic Hypothalamic Glioma (ICHG) DIAGNOSED during the FIRST year of life.

PROGRESSION_DURING_CARBOPLATIN/_V Title copy adjust

Progression DURING Carboplatin / VINCRISTINE

treatment_progr._DURING_Carbo_VCR Multiple Choice Max. 1 copy adjust

1

How do you treat a child progressing during carboplatin / VINCRISTINE chemotherapy?

- (Intensified) CTX (see selection below)
- Targeted monotherapy (e.g. bevacizumab, imatinib) (see selection below)
- Targeted agent like bevacizumab combined with other drug(s)
- Surgery (if safely feasible)
- Surgery (if safely feasible) and continuation of LGG chemotherapy
- Surgery (if safely feasible) and other CTX (see selection below)
- Brachytherapy
- External beam radiotherapy
- Other (specify?)
- Remarks

drugs_in_second_line_(DURING) Multiple Choice copy adjust

2

Which drug(s) do you actually use in second line (drugs listed below identified by literature review)?

(multiple selections are possible in case you apply a multiple-drug regime)

- | | | |
|--|--|---|
| <input type="checkbox"/> Actinomycin | <input type="checkbox"/> | <input type="checkbox"/> Carboplatin |
| <input type="checkbox"/> CCNU | <input type="checkbox"/> Bevacizumab (Avastin) | <input type="checkbox"/> Cyclophosphamide |
| <input type="checkbox"/> Etoposide | <input type="checkbox"/> Cisplatin | <input type="checkbox"/> Ifosfamide |
| <input type="checkbox"/> Imatinib mesylate (Gleevec) | <input type="checkbox"/> Everolimus | <input type="checkbox"/> Irinotecan |
| <input type="checkbox"/> Procarbazine | <input type="checkbox"/> Irinotecan | <input type="checkbox"/> Nilotinib |
| <input type="checkbox"/> Vinblastin | <input type="checkbox"/> Temozolomide | <input type="checkbox"/> Thioguanine |
| | <input type="checkbox"/> Vincristin | <input type="checkbox"/> Other (specify?) |

Remarks

3rd_line_progr._DURING_Carbo_VCR

Multiple Choice Max. 1

copy

adjust

3

What do you consider as third line therapy if not responsive or early progressive ?

- (Intensified) CTX (see selection below)
- Targeted monotherapy (e.g. bevacizumab, imatinib) (see selection below)
- Targeted agent like bevacizumab combined with other drug(s)
- Surgery (if safely feasible)
- Surgery (if safely feasible) and continuation of LGG chemotherapy
- Surgery (if safely feasible) and other CTX (see selection below)
- Brachytherapy
- External beam radiotherapy
- Other (specify?)
- Remarks

Drugs_third_line_(early_progr.)

Multiple Choice

copy

adjust

4

Which drug(s) do you use in third line (drugs listed below identified by literature review)?

(multiple selections are possible in case you apply amultiple-drug regime)

- | | | |
|--|--|--|
| <input type="checkbox"/> Actinomycin | <input type="checkbox"/> | <input type="checkbox"/> Carboplatin |
| <input type="checkbox"/> CCNU | <input type="checkbox"/> Bevacizumab (Avastin) | <input type="checkbox"/> Cyclophosphamide |
| <input type="checkbox"/> Etoposide | <input type="checkbox"/> Cisplatin | <input type="checkbox"/> Ifosfamide |
| <input type="checkbox"/> Imatinib mesylate (Gleevec) | <input type="checkbox"/> Everolimus | <input type="checkbox"/> Irinotecan |
| <input type="checkbox"/> Procarbazine | <input type="checkbox"/> Nilotinib | <input type="checkbox"/> Thioguanine |
| <input type="checkbox"/> Vinblastin | <input type="checkbox"/> Temozolomide | <input type="checkbox"/> Vincristin |
| | | <input type="checkbox"/> Other (specify?) <input type="text"/> |

Remarks

New page

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Next

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44%

reminder_patient_cohort Title copy adjust

All questions below ONLY concern children with Chiasmatic Hypothalamic Glioma (ICHG) DIAGNOSED during the FIRST year of life.

PROGR_DURING_CARBO/_VBL Title copy adjust

Progression DURING Carboplatin / VINBLASTIN

treatment_progr_DURING_Carbo_VBL Multiple Choice Max. 1 copy adjust

5

How do you treat a child progressing during carboplatin / VINBLASTIN chemotherapy?

- (Intensified) CTX (see selection below)
- Targeted monotherapy (e.g. bevacizumab, imatinib) (see selection below)
- Targeted agent like bevacizumab combined with other drug(s)
- Surgery (if safely feasible)
- Surgery (if safely feasible) and continuation of LGG chemotherapy
- Surgery (if safely feasible) and other CTX (see selection below)
- Brachytherapy
- External beam radiotherapy
- Other (specify?)
- Remarks

drugs_in_second_line_(DURING)_VBL Multiple Choice copy adjust

6

Which drug(s) do you actually use in second line (drugs listed below identified by

literature review)?

(multiple selections are possible in case you apply a multiple-drug regime)

Actinomycin

CCNU

Etoposide

Imatinib mesylate (Gleevec)

Procarbazine

Vinblastin

Remarks

Bevacizumab (Avastin)

Cisplatin

Everolimus

Irinotecan

Temozolomide

Vincristin

Carboplatin

Cyclophosphamide

Ifosfamide

Nilotinib

Thioguanine

Other (specify?)

3rd_line_progr_DURING_Carbo_VBL

Multiple Choice Max. 1

copy

adjust

7

What do you consider as third line therapy if not responsive or early progressive ?

- (Intensified) CTX (see selection below)
- Targeted monotherapy (e.g. bevacizumab, imatinib) (see selection below)
- Targeted agent like bevacizumab combined with other drug(s)
- Surgery (if safely feasible)
- Surgery (if safely feasible) and continuation of LGG chemotherapy
- Surgery (if safely feasible) and other CTX (see selection below)
- Brachytherapy
- External beam radiotherapy
- Other (specify?)
- Remarks

Drugs_third_line_(early_progr.)_VBL

Multiple Choice

copy

adjust

8

Which drug(s) do you use in third line (drugs listed below identified by literature review)?

(multiple selections are possible in case you apply a multiple-drug regime)

Actinomycin

CCNU

Etoposide

Imatinib mesylate (Gleevec)

Bevacizumab (Avastin)

Cisplatin

Everolimus

Carboplatin

Cyclophosphamide

Ifosfamide

Nilotinib

Procarbazine

Thioguanine

Remarks

Irinotecan

Vincristin

Temozolomide

Other (specify?)

Vinblastin

New page copy adjust

NEXT

Page: 5 | Progression_AFTER_therapy

previous

56%

reminder_patient_cohort Title copy adjust

All questions below ONLY concern children with Chiasmatic Hypothalamic Glioma (ICHG) DIAGNOSED during the FIRST year of life.

Title_Progression_after_ther Title copy adjust

Progression AFTER therapy

Treatment_AFTER_end_1st_line_CTX Multiple Choice Max. 1 copy adjust

9

How do you treat a child progressing AFTER THE END of primary chemotherapy

- Rechallenging to carboplatin / vincristin or carboplatin / vinblastin
- Other CTX (see selection below)
- Targeted monotherapy (e.g. bevacizumab, imatinib) (see selection below)
- Targeted agent like bevacizumab combined with other drug(s)

- Surgery (if safely feasible)
- Surgery (if safely feasible) and continuation of LGG chemotherapy
- Surgery (if safely feasible) and other CTX (see selection below)
- Brachytherapy
- External beam radiotherapy
- Other (specify?)
- Remarks

Drugs_progr_after_end_1st_line	Multiple Choice	copy	adjust
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10

Which drug(s) do you use in second line (drugs listed below identified by literature review)?

(multiple selections are possible in case you apply amultiple-drug regime)

<input type="checkbox"/> Actinomycin	<input type="checkbox"/>	<input type="checkbox"/> Carboplatin
<input type="checkbox"/> CCNU	<input type="checkbox"/> Bevacizumab (Avastin)	<input type="checkbox"/> Cyclophosphamide
<input type="checkbox"/> Etoposide	<input type="checkbox"/> Cisplatin	<input type="checkbox"/> Ifosfamide
<input type="checkbox"/> Imatinib mesylate (Gleevec)	<input type="checkbox"/> Everolimus	<input type="checkbox"/> Nilotinib
<input type="checkbox"/> Procarbazine	<input type="checkbox"/> Irinotecan	<input type="checkbox"/> Vincristin
<input type="checkbox"/> Thioguanine	<input type="checkbox"/> Vinblastin	<input type="checkbox"/> Temozolomide
<input type="checkbox"/> Remarks <input type="text"/>		<input type="checkbox"/> Other (specify?) <input type="text"/>

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67%	
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reminder_patient_cohort	Title	copy	adjust
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All questions below ONLY concern children with Chiasmatic Hypothalamic Glioma (ICHG) DIAGNOSED during the FIRST year of life.

LENGTH_of_treatment	Title	copy	adjust
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LENGTH of first line treatment

LENGTH_of_treatment	Multiple Choice Max. 1	copy	adjust
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11

How long do you treat in first line?

- 12 months
- 18 months
- other

duration_1st_line_Carbo_VCR	Drop down	copy	adjust
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12

In case of carboplatin / vincristine (e.g. SIOP LGG 2004): do you presently stop after 18 months or add a prolonged maintenance?

:: Please choose :: ▼

contiuring_Carbo_VCR_prolongued	Drop down	copy	adjust
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13

If you prolong 1st line Carbo / VCR, do you add more Carbo / VCR cycles?

:: Please choose :: ▼

Drugs_prolonged_maintenance_actual	Multiple Choice	copy	adjust
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14

If you give other drugs, please specify

(multiple selections are possible in case you apply amultiple-drug regime)

- Actinomycin Carboplatin

<input type="checkbox"/> CCNU	<input type="checkbox"/> Bevacizumab (Avastin)
<input type="checkbox"/> Etoposide	<input type="checkbox"/> Cisplatin <input type="checkbox"/> Cyclophosphamide
<input type="checkbox"/> Imatinib mesylate (Gleevec)	<input type="checkbox"/> Everolimus <input type="checkbox"/> Ifosfamide
<input type="checkbox"/> Procarbazine	<input type="checkbox"/> Irinotecan <input type="checkbox"/> Nilotinib
<input type="checkbox"/> Thioguanine	<input type="checkbox"/> Vincristin <input type="checkbox"/> Temozolomide
<input type="checkbox"/> Remarks	<input type="checkbox"/> Vinblastin <input type="checkbox"/> Other (specify?)
<input type="text"/>	<input type="text"/>

consider_prolonged_maintenance	Drop down	copy	adjust
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15

Would you consider prolonged maintenance of first line therapy?

Drugs_prolonged_maintenance_consider	Multiple Choice	copy	adjust
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16

If so: which therapy?

(multiple selections are possible in case you apply a multiple-drug regime)

<input type="checkbox"/> Actinomycin	<input type="checkbox"/> Bevacizumab (Avastin)	<input type="checkbox"/> Carboplatin
<input type="checkbox"/> CCNU	<input type="checkbox"/> Cisplatin	<input type="checkbox"/> Cyclophosphamide
<input type="checkbox"/> Etoposide	<input type="checkbox"/> Everolimus	<input type="checkbox"/> Ifosfamide
<input type="checkbox"/> Imatinib mesylate (Gleevec)	<input type="checkbox"/> Irinotecan	<input type="checkbox"/> Nilotinib
<input type="checkbox"/> Procarbazine	<input type="checkbox"/> Temozolomide	<input type="checkbox"/> Thioguanine
<input type="checkbox"/> Vinblastin	<input type="checkbox"/> Vincristin	<input type="checkbox"/> Other (specify?)
<input type="checkbox"/> Remarks	<input type="text"/>	
<input type="text"/>		

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Title_Use_of_BVZ Title copy adjust

Use of Bevacizumab in children with chiasmatic hypothalamic glioma

BVZ_availability Drop down copy adjust

17

Was bevacizumab available to you in the past for treatment of children with chiasmatic / hypothalamic glioma?

:: Please choose :: ▼

Experience_with_BVZ_in_infant_OPG Drop down copy adjust

18

Do you have experience in the use of BVZ in children with chiasmatic / hypothalamic glioma?

:: Please choose :: ▼

How_many_treated_BVZ Multiple Choice Max. 1 copy adjust

19

If yes, how many were treated at your centre?

- Not applicable
- 1
- 2 to 5
- 6 to 10
- 11 to 15
- more than 15 (how many?)

Percentage_response_BVZ

Multiple Choice Max. 1

copy

adjust

20

If yes, how many responded with stable disease or regression?

- Not applicable
- 0 to 20 %
- 20 to 40 %
- 40 to 60 %
- more than 60 %
- specify if possible

How_many_BVZ_under_1

Multiple Choice Max. 1

copy

adjust

21

If yes, how many were below one year of age?

- Not applicable
- 1
- 2 to 5
- 6 to 10
- 11 to 15
- more than 15 (how many?)

BVZ_duration

Drop down

copy

adjust

22

How long do you usually treat children with CHG using Bevacizumab?

 ▼

Combination_BVZ

Multiple Choice Max. 1

copy

adjust

23

Was BVZ combined with another drug? if yes, specify.

- No
- Yes

BVZ_complications Multiple Choice copy adjust

24

Where there major complications using BVZ in these children?

- No
- Yes (please specify)

Future_availability_BVZ Multiple Choice Max. 1 copy adjust

25

Would BVZ be available to you in the future for treatment of young children with OPG (outside of a treatment protocol with bevacizumab provided)?

- No
- Yes (please specify)

New page copy adjust

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Page: 8 | RTX

previous

89%

reminder_patient_cohort Title copy adjust

All questions below ONLY concern children with Chiasmatic Hypothalamic Glioma (ICHG) DIAGNOSED during the FIRST year of life.

title_RTX Title copy adjust

Radiation therapy

title_external_RTX	Title	copy	adjust
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External radiation therapy

Age_RTX	Drop down	copy	adjust
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26

Above which age (in years) do you consider applying external beam radiotherapy?
(answer in years)

:: Please choose :: ▼

indications_RTX	Multiple Text Lines	copy	adjust
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27

What do you consider as indications to apply external beam radiotherapy?

1

2

3

4

5

contraindications_RTX	Multiple Text Lines	copy	adjust
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28

What do you consider the most important contra-indications to external beam radiotherapy, i.e. which lead to withholding it?

1

2

3

4

5

title_brachyther	Title	copy	adjust
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Brachytherapy

brachytherapy_option_y-n Drop down copy adjust

29

Do you consider brachytherapy as an option?

brachyther_avail Drop down copy adjust

30

Is it available for your patients?

brachyther_indic Multiple Text Lines copy adjust

31

15.2. If Brachytherapy is available: What are the indication to perform brachytherapy?

1	<input type="text"/>
2	<input type="text"/>
3	<input type="text"/>
4	<input type="text"/>
5	<input type="text"/>

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TITLE_General_issues Title copy adjust

General issues

country Multiple Text Lines copy adjust

32

Country / Oncologic centre

Country

Oncologic centre (place of work)

brain_tu_pts_per_year Multiple Choice copy adjust

33

Please indicate the number of new brain tumour patients at your centre per year?

- less than 5
- 5 to 10
- 10 to 20
- 20 to 30
- 30 to 40
- more than 40

Nr_patients_OPG_per_yr Multiple Choice copy adjust

34

How many new patients with optic pathway glioma are seen at your centre per year?

- none
- 1 to 3
- 4 to 6
- 7 to 10
- 10 to 15
- more than 15

Nr_infants_OPG_5_yrs Multiple Choice copy adjust

35

How many infants with OPG present in five years

- less than 1
- 1
- 2 to 3
- 4 to 6
- 7 to 8
- more than 8
- comments

personal_information Title copy adjust

Personal information

profession Multiple Choice Max. 1 copy adjust

36

Profession

- Paediatric oncologist
- Neurosurgeon
- Radiotherapist
- Other

EXPERIENCE Drop down copy adjust

37

Years of experience

Personal_information Multiple Text Lines copy adjust

38

Please enter personal details below (optional)

Name

email

Open_comments | Essay / text area | copy | adjust

39

If there are issues that have not been raised, please enter your comments:

Submit | Submit button | copy | adjust

Submit

Final text

x | Final Text | copy | adjust

Thank you very much for answering the questionnaire!

Please send us your feedback, comments and remarks

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