

Diagnostics and treatment of diffuse intrinsic pontine glioma:

Where do we stand?

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Dear colleague,

In the SIOPE DIPG Network of the HGG/DIPG working group of SIOP Europe, we have set up a survey to obtain more detailed information about the treatment regimens of DIPG in- and outside Europe. With this data we aim to write a paper about the homo/heterogeneity of treatment of DIPG in Europe and beyond. We would like to ask you to fill in a short survey (+/- 10 min) about the treatment options you have in your institution, as detailed as possible.

Thank you in advance.

Kind regards, also on behalf of Dannis van Vuurden and Vicente Santa-Maria Lopez.

Fatma El-Khouly

[Start survey](#)

1. **Background information participant**

Name

Country

City

Hospital

Function/specialty

DIPG National coordinator? (Yes/No)

DIPG trial coordinator? (Yes/No)

2. **How many DIPG patients do you treat per year or (in case of national/trial coordinator) do you oversee per year?**

3. **How many of these DIPG patients participate in ongoing clinical trials?**

☐ A < 25%

☐ B 25-50%

☐ C 50-75%

☐ D > 75%

4. Which clinical trials are currently ongoing in your country? (please mention trial name and hospital)

5. Are DIPG patients biopsied in your hospital?

☐ A Yes, all patients are biopsied

☐ B Most patients are biopsied

☐ C Patients are biopsied infrequently

☐ D No, we never perform a biopsy on DIPG patients

6. Is it confusing for your daily clinical routine that there is now a radiological diagnosis of DIPG and a neuropathological diagnosis of a diffuse midline glioma WHO IV, H3K27M mutant? If yes, could you briefly explain these difficulties/confusions?

☐ A Yes

☐ B No

7. Do you treat non-pontine diffuse midline gliomas WHO IV, H3K27M mutant, like DIPG? If no, could you briefly explain how you treat these patients?

☐ A Yes

☐ B No

Next - First line therapy

First line therapy

The following questions are about initial treatment, directly after diagnosis.

8. When a patient is diagnosed with DIPG, what do you consider to be the standard first line treatment? Please mention (generic) name, dose, frequency and treatment duration.

☐ A Radiotherapy only

☐ B Chemotherapy only

☐ C Radiotherapy + chemotherapy

☐ D Immunotherapy

☐ E No treatment

☐ F Other

9. There seems to be a difference between younger (≤ 3 years) and older (> 3 years) children suffering from DIPG. Younger children seem to have a better prognosis. Do you treat these younger children different than older children at diagnosis?

☐ A Yes

☐ B No

10. If yes, please describe what you do differently with these children.

11. Other comments regarding first line therapy

Next - Second line therapy

Second line therapy

The following questions are about the treatment you offer after first progression.

12. When a patient has progressive disease after initial therapy, what do you consider to be the most appropriate second line treatment? Please mention (generic) name, dose, frequency and treatment duration.

☐ A Radiotherapy only

☐ B Chemotherapy only

☐ C Radiotherapy + chemotherapy

☐ D Immunotherapy

☐ E No treatment

☐ F Other

13. Do you treat younger children (≤ 3 years) different than older children (> 3 years) after first progression?

☐ A Yes

☐ B No

14. If yes, please describe what you do differently with these children.

15. Other comments regarding second line therapy (after first progression).

[Next - Third line therapy](#)

Third line therapy

The following questions are about the treatment you offer after second progression.

16. When a patient has progressive disease for the second time, what do you consider to be the most appropriate third line treatment? Please mention (generic) name, dose, frequency and treatment duration.

☐ A Radiotherapy only

☐ B Chemotherapy only

☐ C Radiotherapy + chemotherapy

☐ D Immunotherapy

☐ E No treatment

☐ F Other

17. Do you treat younger children (≤ 3 years) different than older children (> 3 years) after second progression?

☐ A Yes

☐ B No

18. If yes, please describe what you do differently with these children.

19. Other comments regarding third line therapy (after second progression).

[Finish and save survey](#)

Thank you for your contribution to this survey. After analyzing the data, we will inform you about the results.