Neuro-Oncology Practice

12(S1), i26-i28, 2025 | https://doi.org/10.1093/nop/npae081 | Advance Access date 25 November 2024

Vorasidenib: Patient and caregiver information sheet

Mallika P. Patel, Jennifer N. Serventi, Erin M. Dunbar, Kathy Oliver, Karin Piil^o, Tatjana Seute^o, and Susan Chang^o

All author affiliations are listed at the end of the article.

Corresponding Author: Mallika P. Patel, PharmD, CPP, Department of Pharmacy, Duke University Medical Center, PO Box 3624, Durham, NC 27710 (mallika.patel@duke.edu).

Vorasidenib: patient and caregiver information sheet

This handout gives a brief overview of how to safely take vorasidenib. Talk to your healthcare team for instructions regarding your treatment, as there may be adjustments to your concurrent medicines according to your blood work or other illnesses.

About vorasidenib and IDH-mutant gliomas

Gliomas are malignant tumors in the brain that arise from supportive cells called glial cells that need energy to grow and spread. Gliomas are classified into grades based on how quickly they are likely to grow and spread. Some gliomas have changes in their genetic code, called mutations, that can generate abnormal enzymes that alter their behavior. These mutations and the abnormal enzymes are valuable markers to identify key information about the tumor's speed and pattern of growth. Gliomas with mutations in genes called isocitrate dehydrogenase 1 (IDH1) and isocitrate dehydrogenase 2 (IDH2) are often called IDH-mutant (mIDH) gliomas. For a long time, it has been known that mIDH gliomas generally have a more favorable behavior and treatment response compared to tumors without this mutation. Knowing your mutation is a piece of information about your tumor's pattern of growth.

A category of medicines called mIDH inhibitors directly blocks the mutant IDH enzymes and does not affect the brain or body cells that do not have this mutation. *Vorasidenib* is a chemotherapy medicine that directly blocks IDH1 and IDH2 mutations and can work in mIDH glioma treatment.

Know the difference: traditional chemotherapy vs vorasidenib

- Current standard treatments for people with mIDH glioma include surgery, radiation, and traditional chemotherapy.
- mIDH inhibitors are a new type of medicine. They target only the mutated IDH1 and IDH2 cells and may be easier to tolerate than traditional chemotherapy.
- There is no information yet about the long-term effects of vorasidenib on patients or how much benefit there may be in terms of survival.
- There remain questions about the use of vorasidenib in other tumors, the appropriate amount of time to take the medicine, and whether adding this to other treatments may be useful.
- In the recent clinical trial called INDIGO¹, patients with lowgrade mIDH1 and mIDH2 gliomas, who had received a biopsy or surgery, were randomly assigned to receive daily treatment either with a mIDH inhibitor called vorasidenib or placebo (sugar pill).
- After 14 months of follow-up, the study¹ found that vorasidenib appeared to slow tumor growth and few patients (3%) had to stop the medicine due to side effects.
- All patients with mIDH gliomas are encouraged to talk to their healthcare team about the use of vorasidenib and ask about any potential clinical trials for which they may be eligible.

How to take vorasidenib

- Take vorasidenib once daily on an empty stomach with water.
- Avoid eating 2 hours before and after taking the pill. Taking vorasidenib with food reduces the amount of medicine absorbed into your stomach.
- Take at about the same time every day.

Neuro-Oncology

- Using a medicine diary may be helpful to prevent missing doses. You can find an example of one to use online. You can also set calendar reminders or alarms to help you remember to take this medicine consistently.
- Missed dose: if you miss a dose and it is less than 12 hours to the next dose, skip it. Do not double up doses.
- Other medicines: tell your healthcare team about other medicines or supplements you take.

Handling and storage

- Keep vorasidenib away from children and pets.
- Store at room temperature, away from humid places like bathrooms.

Side effects

- Vorasidenib may affect your liver function. Your healthcare team will monitor this with blood tests.
- Other common side effects include tiredness, headache, diarrhea, nausea, dizziness, seizures, and constipation.
- Most side effects have been mild, and vorasidenib tends to be better tolerated than traditional chemotherapy.
- If you have side effects, contact your healthcare team for help with managing these.
- Make sure to have the contact details for your healthcare team for both regular hours and emergencies.
- It is unlikely that this medicine will stop your ability to participate in any of your normal activities.

Reproductive health

- Do not become pregnant or breastfeed while taking vorasidenib, and for 3 months after stopping.
- Use effective birth control during treatment and for 3 months after.
- The decision to begin a potentially lengthy treatment plan that impacts families and reproduction is a personal one. Please take time to think about your options and discuss them with your partner and healthcare team prior to starting vorasidenib.

Access and assistance

- Talk to your healthcare team about how you can be prescribed vorasidenib.
- Ask your healthcare team how much vorasidenib may cost you.
- Discuss any financial concerns with your healthcare team.

For caregivers

- Caregivers should help monitor your symptoms and side effects.
- Encourage your caregiver to report any issues or concerns to the healthcare team.

Before starting vorasidenib, ask your healthcare team these questions

- How often do I need blood tests?
- Who should I contact if I have side effects between appointments?
- How can we plan my treatment if I want to start a family?
- How long will I be taking this medicine?
- What other treatments are available that I can consider?

Authors

Mallika P. Patel, PharmD, CPP; Jennifer N. Serventi, PAC, MS; Erin M. Dunbar, MD; Kathy Oliver, BA; Karin Piil, PhD; Tatjana Seute, MD; Susan Chang, MD

Please note that this handout is a general overview, and individual circumstances may vary. Always consult with your healthcare team and explore personalized options based on your specific needs. The information contained in this handout is based on available information as of July 2024.

Keywords

patient education | IDH-mutant gliomas

Supplement sponsorship

This article appears as part of the supplement "Practical Management of Patients With IDH-Mutant Glioma," sponsored by Servier.

Acknowledgments

We would like to thank members of the UCSF Thrivers community of peer support volunteers who reviewed and provided useful feedback for this patient information sheet.

Conflict of interest statement

M.P.P.: participant in the Servier Glioma Center of Excellence. J.N.S.: none. E.D.: none. K.O.: works with Servier on their international low-grade glioma patient committee and is involved with the Servier low-grade glioma patient pathway initiative. K.P.: member of The Global Glioma Education Steering Committee of Servier. T.S.: none. S.C.: none.

Neuro-Oncology, University of Rochester Medical Center, Rochester, New York, USA (J.N.S.); Piedmont Physicians Neuro Oncology, Piedmont Atlanta Hospital, Atlanta, Georgia, USA (E.M.D.); International Brain Tumor Alliance (IBTA), Tadworth, Surrey, UK (K.O.); Department of People and Technology, Roskilde University, Roskilde, Denmark (K.P.); Department of Neuro-oncology, UMC Utrecht, Utrecht, The Netherlands (T.S.); Neurological Surgery, UCSF Weill Institute for Neurosciences, San Francisco, California, USA (S.C.)

Affiliations

The Preston Robert Tisch Brain Tumor Center, Duke University Medical Center, Durham, North Carolina, USA (M.P.P.); Department of Pharmacy, Duke University Medical Center, Durham, North Carolina, USA (M.P.P.); Department of Neurology,

Reference

 Mellinghoff IK, van den Bent MJ, Blumenthal DT, et al.; INDIGO Trial Investigators. Vorasidenib in IDH1- or IDH2-mutant low-grade glioma. N Engl J Med. 2023;389(7):589–601.