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Dear Members of the Pharmaceutical Benefits Advisory Committee,

**Re: Strong Support for Listing of Vorasidenib on the Pharmaceutical Benefits Scheme (PBS)**

On behalf of the Brain Tumour Alliance Australia (BTAA) and the patients and families we represent, I am writing to express our strongest support for the listing of Vorasidenib on the Pharmaceutical Benefits Scheme (PBS) for the treatment of IDH-mutant diffuse glioma (lower-grade glioma, LGG).

The BTAA is a highly regarded national organisation representing people affected by brain tumours in Australia. We provide information, support, advocacy, and a community of care for patients, families, and carers. Our services include a national phone support line, printed and digital information resources, peer-to-peer support, patient forums, and direct advocacy for timely, equitable, and person-centered care.

BTAA also leads Head to the Hill, Australia's only national brain cancer advocacy event. This initiative brings together patients, families, clinicians, researchers, and organisations from across the country to engage directly with Members of Parliament about the urgent needs of the brain cancer community, helping ensure policy and funding reflect the lived experience of those affected.

The burden of lower-grade glioma (LGG) is often misunderstood or underestimated. Despite being considered a "slower-growing" brain cancer, LGG patients typically experience prolonged and accumulating disability over many years. Most patients endure a wide range of physical, cognitive, psycho-social, and emotional impairments—including seizures, speech and memory loss, fatigue, anxiety, and depression. These impacts severely disrupt every aspect of life: the ability to work, study, parent, plan, or live independently. They also deeply affect family members, partners, and carers, often leading to financial hardship, caregiver burnout, and long-term emotional trauma.

Beyond individual suffering, LGG imposes significant costs on the broader health, disability, and welfare systems. Many patients require lifelong NDIS support and frequent hospitalisations, adding to the societal burden of an already devastating disease. On average, LGG patients regularly require several times higher NDIS funding than the national average of NDIS Participant funding, which reiterates the level of impact.

Vorasidenib offers the first meaningful therapeutic advance for this patient population in decades. It is an oral, targeted therapy that inhibits mutant IDH1 and IDH2 enzymes, which drive the growth of IDH-mutant gliomas. By interrupting the disease process at its source, Vorasidenib may delay tumour progression and defer the need for damaging treatments such as radiotherapy and chemotherapy.

The critical INDIGO phase 3 trial showed that Vorasidenib significantly extended progression-free survival—27.7 months versus 11.1 months for placebo—and delayed the need for next intervention. Crucially, this delay gives patients the ability to preserve cognitive function, independence, and quality of life at a time when those abilities matter most.

It is important to note that in recent decades, there have been very few—if any—new drugs offering real hope to brain cancer patients. This absence of innovation has had a devastating emotional impact on an already vulnerable group of terminally ill Australians. The opportunity represented by Vorasidenib is rare and deeply meaningful.

Coupled with the current lack of government awareness around the real-world impacts and urgent needs for better treatments, a decision not to list Vorasidenib on the PBS would only deepen the despair of a community already forced to fight for visibility, support, and dignity. For these Australians, it is not just about access to a drug—it is about hope, fairness, and survival.

BTAA has a long history of supporting brain tumour patients and families across Australia. Each day, BTAA connects with patients and families and understands all brain tumours including LGG, treatment options and subsequent challenges. Our committee members – current and past – are patients and carers of people who have succumbed or continually struggle with these LGGs. We fully understand the problem set and the importance of Vorasidenib being PBS listed.

BTAA strongly urges the PBAC to recognise the extraordinary burden borne by people living with lower-grade glioma, the proven clinical benefit of Vorasidenib, and the transformative impact PBS listing would have on equity and quality of life.

We thank the Committee for its consideration and welcome the opportunity to provide further consumer insight or testimony in support of this submission.

Yours sincerely,



**Craig Cardinal**

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