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Patients gather in Canberra to call for access ahead of next week's PBAC meeting

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LATEST NEWS BIOPHARMA NEWS OF THE DAY

Patients will gather at Parliament House in Canberra today for an event to raise attention ahead of the Pharmaceutical Benefits Advisory Committee's consideration of a new cancer therapy.

The committee will consider MSD's WELIREG (belzutifan) for Von Hippel-Lindau (VHL) disease at its meeting next week.

VHL is a rare, predominantly inherited cancer caused by a genetic mutation, affecting 1 in 36,000 people in Australia. It is characterised by tumours and fluid-filled sacs forming in different body parts. There is a 50 per cent chance of passing the gene on to children.

Surgery or radiation therapy are the current standard of care treatment.

The event in Canberra, organised by NeuroEndocrine Cancer Australia, is sponsored by MSD. It is hosted by the independent MP Zali Steggal and will be opened by Assistant Health Minister Ged Kearney.

“I join the many Australians advocating for belzutifan to be added to the PBS. No one, including a brave member of my electorate, should have to choose between available treatment or suffering without care because that treatment is completely cost prohibitive," said Ms Steggal in a statement. "I urge the government to act on the recommendations from the recent Inquiry into Rare Cancers, including Neuroendocrine Cancer, and list Belzutifan on the PBS.”

One VHL patient, Simon Goodrich, is currently accessing WELIREG privately. He recently told Network Ten's The Project that his tumour had shrunk by 65 per cent since starting treatment. Other patients have relocated overseas to access the treatment.

A recent petition calling for the funding of WELIREG attracted almost 18,000 signatures. Listing the therapy on the PBS would benefit around 500 patients.

In May, the report of a Senate inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers recommended the Government adjust regulatory and reimbursement processes to improve access to medicines that treat rare and less common cancers, including neuroendocrine cancer.

Meredith Cummins, the CEO of NeuroEndocrine Cancer Australia, said, “As a result of the Senate Inquiry, we thank the Senate for recognising the need for specialised neuroendocrine cancer care and we look forward to working with the government to action these recommendations and improve outcomes for those living with neuroendocrine cancer.

"VHL patients do not have equitable or affordable access to medications such Belzutifan to control their tumours – without this medication their lives are plagued with ongoing surgery, reduced quality of life, reduced hope and the opportunity to have a life with their family – TIME is running out for many."