



Migraine and Headache Australia

PO Box 579

Crows Nest

NSW 1585

Ph: 1800 886 600

[www.headacheaustralia.org.au](http://www.headacheaustralia.org.au)

## Disappointment With The Breakdown In The PBS Process

### MEDIA STATEMENT

28 October 2019

**Sydney, Australia, 28 October 2019** - Novartis has withdrawn its third submission to the Pharmaceutical Benefits Advisory Committee (PBAC) after two failed attempts to receive approval for coverage by the Pharmaceutical Benefits Scheme (PBS).

The PBS is an essential Australian service which makes expensive and complex drugs affordable for many people who would otherwise be unable to afford or access the treatment. Many cancer treatments are listed on the PBS which provide vital treatment options.

The latest treatment from Novartis is a new generation treatment which employs a similar mechanism of action to some cancer treatments. It is a monoclonal antibody that targets Calcitonin Gene-Related Peptides (CGRP) which are involved in the cascade of a migraine attack. This treatment helps prevent migraine attacks and is the first medical treatment specifically designed for migraine prevention.

CGRP was first discovered in 1982 and over the last 37 years research has led to the development of this new generation of treatment. Multiple research studies have demonstrated the efficacy, safety and cost effectiveness of this treatment. It has provided hope to many Australians struggling with chronic migraine.

Migraine affects 4.9 million Australians according to a recent Deloitte Report. It is more common than epilepsy, diabetes and asthma. Like other chronic diseases, migraine affects people differently. Some may experience relatively infrequent attacks that respond well to first-line treatment, while others may be completely debilitated by severe and disabling attacks for most of any given month. For those living with this severe form of migraine with 15 days or more affected it is referred to a chronic migraine. There is no cure for migraine and patients respond differently to different treatments which is why having more proven safe and effective options is so important.

There is an estimated 400,000 Australians living with chronic migraine which is the group for which this treatment is designed. These are the most severe and hardest hit by the burden of migraine.

Migraine can take everything worth living for. It can affect your work, career, your relationships with friends and family and your ability to lead a normal life.

Depression and anxiety is 4 times more common in those with chronic migraine. Chronic migraine is also much more likely to lead to other chronic conditions associated with chronic pain.

The cost of CGRP treatments without PBS support is approximately \$800 per month. This is beyond the affordability of most people living with chronic migraine. The nature of chronic migraine makes work difficult or impossible for many patients who experience severe pain and symptoms like nausea, vomiting, visual impairment, light sensitivity, fatigue, and brain fog.

The new treatments have been described by some as “life-changing”. It has provided hope to many Australians living with frequent migraine. Disappointingly it has been rejected twice by the PBAC.

The PBAC is the committee responsible for making recommendations to the government who typically implement the recommendation.

Limited information is available from the PBAC or from Novartis as to the details regarding its withdrawal. Richard Tew, General Manager Novartis Pharmaceuticals Australia and New Zealand said: “This decision has not been taken lightly and follows thorough consideration of recent developments in the reimbursement of innovative migraine treatments in Australia.”

A current migraine preventive treatment covered by the PBS is Botox. Botox treats numerous medical conditions and may also be used to help prevent migraine when a specific migraine injection protocol is followed. When used for migraine treatment, patients do not receive the typical cosmetic benefits for which Botox is well known.

Botox can be an effective treatment for migraine but there is no one treatment that works for everyone. Botox is manufactured by Allergan which receives limited support from the PBS. There are conditions attached with the PBS coverage. One condition is a “cap” or limit to the amount covered by the PBS. If that cap is reached then no further funding support is provided by the PBS to the manufacturer and the organisation essentially funds the treatment itself for the patient.

The PBAC has suggested that this new class of CGRP treatment for migraine prevention share the same cap currently used by Botox. Details about the amount set in the cap are limited, however, Migraine and Headache Australia understands that this amount is so small that the cap budget set for the entire year is reached by Botox alone within a few months.

Not only is this cap insufficient for Botox currently, but the PBAC has indicated that the CGRPs are to share this same cap with Botox.

Migraine today is underdiagnosed, undertreated and poorly managed. Studies report that less than one third of patients who qualify for preventive treatment are currently using them. Without expanding the cap to provide adequate support for Australians living with chronic migraine, people will continue to suffer.

Migraine and Headache Australia’s CEO Trevor Thompson said: “We are disappointed that despite over 2,000 unique and written submissions from the migraine community to the PBAC, little has changed. Migraine still does not appear to be a priority nor has the level of support changed with the arrival this new generation treatment.”

Patients have a fundamental human right to access effective treatments at a fair price. The Australian government has put in place the PBS system for exactly this purpose yet appears to have turned its back on this life-changing treatment.

Migraine and Headache Australia is committed to supporting patients living with frequent migraine and calls for a humane approach for fair and affordable access to proven and cost-effective migraine prevention.

### **IMPORTANT NOTES:**

- Aimovig will still be available on private prescription, costing approximately \$800 a month.
- Patients currently on the Patient Familiarisation Program (PFP) will continue to receive Aimovig for free until April 30, 2020.
- Affected patients are urged to talk to their neurologist about their options, and join the Headache Australia Support Group on Facebook.
- More information about the current is available on the Headache Australia website at <https://headacheaustralia.org.au/pbac/>
- The following contacts are available for patients:
  - Novartis Medical Information – 1800 671 203 / [medinfo.phauno@novartis.com](mailto:medinfo.phauno@novartis.com)
  - My Aim Program (Patient Familiarisation Program) – 1800 979 607 / [PFP@myaimprogram.com.au](mailto:PFP@myaimprogram.com.au)

---

### **About**

Migraine and Headache Australia is the only charitable organization in Australia that aims to support the more than 5 million Australians affected by headache and migraine. Its mission is to provide reliable information, advocacy and support for the patient community. Migraine and Headache Australia is a division of the Brain Foundation. The Brain Foundation was established in 1970 by members of the Australian Association of Neurologists and the Neurosurgical Society of Australasia to reduce the incidence and impact of brain, spine and nerve disorders, diseases and injuries through the provision of support, community education and research.

Migraine and Headache Australia is in the process of changing its name. It is formerly known as Headache Australia.

### **Language**

Headache Australia recommends the use of the CHAMP language guide when discussing migraine:

<https://headachemigraine.org/wp-content/uploads/CHAMP-Language-Guide-Web.pdf>

### **Disclaimer**

Headache Australia has received funding in the past from Novartis. This statement has been made independently. Headache Australia is not currently receiving funding or funded in any capacity from Novartis.

### **Contact**

Ph: 1800 886 600

W: [www.headacheaustralia.org.au](http://www.headacheaustralia.org.au)

E: [info@brainfoundation.org.au](mailto:info@brainfoundation.org.au)