



# Allergy & Anaphylaxis Australia<sup>®</sup>

Professor Andrew Wilson  
Chair, Pharmaceutical Benefits Advisory Committee (PBAC)  
MDP 952, GPO Box 9848  
Canberra, ACT 2601

23rd January 2023

Dear Professor Wilson,

Re: Jorveza<sup>®</sup> (Budesonide) for eosinophilic oesophagitis (EoE) change to current Pharmaceutical Benefits Scheme (PBS) listing.

Allergy & Anaphylaxis Australia (A&AA) welcomes the opportunity to lodge our comments in support of the submission for Jorveza<sup>®</sup> which is on the March 2023 Pharmaceutical Benefits Advisory Committee (PBAC) meeting agenda. Jorveza<sup>®</sup> was PBS listed in May 2022 specifically for the treatment of EoE. This application is for a change to the current Pharmaceutical Benefits Scheme (PBS) listing, for Jorveza<sup>®</sup> tablet 500 micrograms or tablet 1 mg (orally disintegrating) for EoE. The proposed changes address issues in the current listing which are potentially reducing access to Jorveza<sup>®</sup> for some patients with EoE. These issues are:

- The requirement for a gastroenterologist to prescribe Jorveza<sup>®</sup>
- The requirement for endoscopy to confirm improvement with Jorveza<sup>®</sup>
- Uncertainty about the number of biopsies required at endoscopy to initiate treatment with Jorveza<sup>®</sup>

A&AA is a registered charity, established in 1993, to inform and support those affected by allergy and anaphylaxis. A&AA is dedicated to assisting individuals, their caregivers and all in the community in the management of allergic conditions. A&AA's aim is to enable individuals and their families to enjoy an optimal quality of life whilst minimising risk to their health and wellbeing. We are a part of an international alliance of like-minded organisations and work closely with peak medical bodies including the Australasian Society of Clinical Immunology and Allergy (ASCIA).

A&AA supports people with EoE, which currently affects about 1 in 1000 Australians<sup>1</sup> (both children and adults). It is a debilitating disease that has no cure. It occurs when there is an excess of eosinophils in the lining of the oesophagus. The symptoms of EoE are varied and can result in inflammation, permanent scarring and narrowing of the oesophagus. This then exacerbates difficulty swallowing and food can get

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stuck in the oesophagus. People sometimes require hospitalisation to remove impacted food and to dilate the narrowed oesophagus.

Currently, the goal of treatment is to improve symptoms by eliminating or reducing the number of eosinophils in the oesophagus. Previously, medications used for other allergic conditions such as allergic asthma have been used to treat EoE. Asthma steroid medications such as Flixotide (Fluticasone propionate) and Pulmicort (Budesonide) have been sprayed into the mouth and/or swallowed to try to get the steroid medication to the oesophagus, and steroid liquid has been mixed into a slurry and swallowed. Jorveza® is a new medication that contains Budesonide in tablet form that dissolves in the mouth and can be swallowed, therefore coating the oesophagus.

EoE can severely impact quality of life, therefore Jorveza® should be an available option to all whether they are managed by their treating gastroenterologist OR clinical immunology/allergy specialist OR other specialist with expertise in diagnosis and management of EoE, especially in rural/remote areas. It is important to understand that while many adults with EoE are only under the care of a gastroenterologist, many children and teens are already under the care of a clinical immunology/allergy specialist when they develop EoE as they often also have IgE mediated food allergy and other allergic conditions. Therefore, it would be appropriate for clinical immunology/allergy specialists or other specialists with expertise in diagnosis and management of EoE to be able to prescribe Jorveza®. Sometimes a gastroenterologist is involved only for the purpose of performing the gastroscopy for histological diagnosis and they then refer the patient back to the clinical immunology/allergy specialist for ongoing management. A&AA therefore believe it is reasonable to allow clinical immunology/allergy specialists or other specialists with expertise in diagnosis and management of EoE (especially in rural/remote areas) to prescribe Jorveza® on an ongoing basis once an initial histological diagnosis has been made on endoscopy.

One of the challenges in EoE management that we are aware of is the need for an endoscopy 8-10 weeks after commencing Jorveza®. A&AA strongly supports the need for a specialist with experience in EoE management and treatment to confirm Jorveza® is improving EoE management however the need for this to only happen with proof via an endoscopy is onerous for people with EoE, gastroenterologists, clinical immunology/allergy specialists and the healthcare system. When someone is prescribed Jorveza® after being shown to fit the criteria for prescription and they report a significant reduction in severity of symptoms, especially when the only change in care has been the addition of Jorveza® as a treatment, an endoscopy within an 8-10 week period post commencement to objectively prove a reduction in eosinophils should not be required. Long wait lists for gastroenterologists and operating theatre bookings, even with private health insurance, need to be factored in to the requirements, especially when consumer feedback suggests this further impacts health and wellbeing (including mental wellbeing) and the healthcare system.

A&AA has also been made aware that there is a lack of clarity about the number of biopsies required at the time of endoscopy before approval is given to commence treatment with Jorveza®. A&AA encourage clarity about the criteria for authority approvals to ensure that people are not inadvertently denied access to this life changing treatment.

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As a consumer advocacy organisation, A&AA has heard from many people about the difficulty in managing EoE and so we welcome the opportunity for them all to have access to a proven medication that is easy to use, safe and efficacious at improving their symptoms and quality of life after consultation with experts in EoE. There is also a great cost to both the individual with EoE and to the healthcare system of delayed and interrupted treatment and the associated complications of inadequately treated EoE such as repeated dilatations and hospitalisations for removal of impacted food. Any measures to address barriers to accessing Jorveza<sup>®</sup> based on endoscopy scheduling, gastroenterologist availability or number of biopsies would be welcome by A&AA.

Yours sincerely,

Maria Said AM  
**Chief Executive Officer**  
**Allergy & Anaphylaxis Australia**

## Reference

1. ASCIA [www.allergy.org.au/patients/food-other-adverse-reactions/eosinophilic-oesophagitis](http://www.allergy.org.au/patients/food-other-adverse-reactions/eosinophilic-oesophagitis)

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