

PBAC Secretariat - MDP 952 Department of Health and Ageing GPO Box 9848 Canberra ACT 2601

January 20th, 2022

To whom it may concern:

Please find the submission of Allergy & Anaphylaxis Australia to the Pharmaceutical Benefits Advisory Committee (PBAC) supporting the Pharmaceutical Benefits Scheme (PBS) listing of Dupilumab (Dupixent®) for the treatment of severe atopic dermatitis (commonly known as eczema) in children aged 6 to 11 years.

## Background

Allergy & Anaphylaxis Australia (A&AA) is a charitable, non-profit organisation established in 1993 to support and assist those affected by allergic disease including eczema. 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.

A&AA strives to raise awareness of allergic disease in the community and provides evidence-based information, resources, and services to support children and adults living with allergic disease and those who care for them. A&AA has members across all states and territories of Australia. We have a Medical Advisory Board that consists of several allergy specialists who are also members of Australia's peak medical body, ASCIA (the Australasian Society of Clinical Immunology and Allergy). A&AA and ASCIA have partnered to progress the National Allergy Strategy – www.nationalallergystrategy.org.au

## Submission

A&AA is grateful for the opportunity to forward a submission expressing the dire need for Dupilumab to be PBS listed for children with severe eczema aged 6 to 11 years.

PBS listing of Dupilumab for people aged 12 years and over has been life changing. A&AA are aware of many people whose quality of life has improved markedly since the PBS listing in March 2021. The testimonials of those currently taking the medication show that it has indeed been life changing for many. Philip, a man in his 50's who has suffered with eczema all his life, has spoken with A&AA about how his life has changed since starting on Dupilumab almost a year ago. Philip is enjoying life now that he does not live through the lens of eczema that controlled his life. He feels less stressed and has greater confidence. His mood has significantly improved, he is not constantly scratching and is able to sleep through the night. Philip does not need to change his bed sheets every day as they are no longer blood-stained, and he does not shed his skin like he used to. Philip can spend quality time with his grandchildren who love to climb all over him and spend time outside in our hot humid summer. Although he has had flares, he is able to control them more effectively when they happen. Dupilumab has not only improved Philip's quality of life (QoL) but also that of his family.

In 2019 Mr Trent Zimmerman MP and Minister for Health, the Hon Greg Hunt MP, announced a Parliamentary Inquiry into Allergies and Anaphylaxis. Many of the two hundred and fifty-two submissions made to the inquiry spoke of life with multiple allergic disease states including eczema. Australians described the impact, including the economic impact, of allergic disease on QoL with many referring specifically to eczema. These submissions were made by parents of children with eczema as well as adults living with eczema. Unfortunately, it is not just those over 12 years who suffer with this debilitating condition. A&AA is currently waiting for Minister Greg Hunt MP to release his response to the report and recommendations handed down by Trent Zimmerman and the Standing Committee.

Many with eczema also have other allergic conditions, and often each family unit has multiple members with multiple allergic disease states. The financial burden of life with allergic disease was a common thread in these submissions. PBS listing of a medication to treat one of their severe disease states (i.e., eczema), would help alleviate some of the financial burden and give children with severe eczema some reprieve from their pain and suffering while they continue life with allergic disease which, for the most part, is not curable.

The severe eczema of a family member impacts the QoL of all family members and this is accentuated when the family member with severe eczema is a child. For these reasons, as well as the QoL of the 6-11yr old with eczema, Dupilumab should be PBS listed. A successful, evidence-based treatment that helps improve not only the

skin of a child but also their self-esteem and self-confidence needs to be accessible to 6-11year old children with severe eczema who have not responded effectively to topical treatments. Children with a visible special need that often isolates them and draws hurtful comments from peers in social and school environments should seriously be considered for safe, new affordable treatments proven to work, at the earliest possible time.

Children with severe eczema who have failed to respond adequately to topical treatments have limited further treatment options. They deserve to be offered the same affordable access to Dupilumab as older Australians, especially as the safety profile in children is similar to that in adolescents and adults. Access to Dupilumab has the potential to greatly improve the child's QoL and reduce the need for ongoing intensive eczema treatment including wet dressings, bleach baths (which take even more time when a child is sleep deprived and irritable) and antibiotics when skin becomes infected.

We acknowledge the challenges of the Australian government and the many health conditions needing urgent attention and funding; however, we cannot ignore the severe impact of debilitating eczema on Australians of all ages with allergic disease. A&AA strongly supports the need for PBS listing of Dupilumab for children aged 6 - 11 years making it an affordable treatment for the majority of parents/carers.

Yours faithfully,

Maria Said CEO Allergy & Anaphylaxis Australia