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Global Healthy Living Foundation Australia and CreakyJoints Australia

Submission to support the expanded listing of apremilast (Otezla®) on the PBS for the treatment of severe chronic plaque psoriasis

For consideration at the November 2023 PBAC Meeting

These comments are submitted by [CreakyJoints Australia](#) and [Global Healthy Living Foundation Australia](#) (GHLF Australia) on behalf of our patient community. We appreciate the opportunity to provide this submission.

PBAC public consultation survey

Q1: Please outline your experience with the medical/health condition

CreakyJoints Australia/GHLF Australia

GHLF Australia is a not-for-profit organisation founded in 2015. GHLF Australia is part of the US-based Global Healthy Living Foundation (GHLF), a non-profit organisation whose mission is to improve the quality of life for people with chronic illness.

Established in 2014 and incorporated in 2016, GHLF Australia is the parent organisation of CreakyJoints Australia, the vibrant online patient community for autoimmune and inflammatory arthritis patients and their families throughout Australia.

Drawing on nearly two decades of foundational knowledge, success and the reputation of GHLF and CreakyJoints, GHLF Australia aims to localise, mobilise and engage the Australian patient and caregiver community and to provide education, advocacy and research for better health outcomes.

CreakyJoints Australia connects arthritis patients with current and relevant disease-specific information and support across a spectrum of arthritis conditions (of which there are more than 100), using a diverse set of digital platforms.

Our experience with psoriasis

Psoriatic arthritis (PsA) is one of the main conditions members of our CJA community live with. We also know that 85 per cent of people with PsA also have psoriasis.¹ Therefore, we have an interest in psoriasis as a comorbidity for these CJA members.

GHLF Australia provides education, support, research and advocacy for people living with a broad range of chronic conditions. We have a psoriasis hub on our website (<https://ghlf.org.au/psoriasis>) dedicated to promoting awareness of psoriasis as far more than just a skin condition. Our hub also helps to empower people with psoriasis to learn more about the condition and how to manage it holistically.

We have worked closely with people from the following organisations to gather valuable patient insights into daily life with psoriasis.

- Psoriasis Australia
- Psoriasis and Psoriatic Arthritis in Australia peer support group on Facebook
- Australian Psoriatic Arthritis Warriors peer support group on Facebook

We have also conducted two focus groups for people with psoriasis with the support of Amgen Australia.

Our GHLF and CreakyJoints colleagues in the US have run extensive psoriasis awareness campaigns and created a large volume of psoriasis content over the years. Our Australian team has drawn on their expertise to create similar resources for people in our community.

The lived experience of chronic plaque psoriasis

Through our activities described above, our organisation has heard from hundreds of people with psoriasis over the years. Through their stories, we have gained a sound understanding of what it is like to live with psoriasis, how they manage it and the support (or lack of it) they have received from others.

For many people with CPP, the mental and social impacts of the condition are as difficult to deal with as the physical symptoms. Until recent years, these impacts were barely noted or often dismissed as unimportant by treating doctors. As a result, people with the condition were left to deal with feelings such as loneliness and embarrassment on their own. This was especially difficult for children, who often did not have the condition explained to them or who were left out of the decisions related to their care.

The risk of developing comorbidities such as psoriatic arthritis was also often left out of the conversation during medical appointments. As a result, the emergence of new symptoms such as painful joints or fatigue was (and sometimes still is) overlooked or dismissed by treating doctors.

We know even mild cases of CPP can cause a person to feel very distressed or isolated, and as such all patients deserve the option to access as many of the most up-to-date treatments as possible. It has also been proven² that effective treatment won't just clear the skin but may also help patients lower their chances of developing associated conditions.

¹ CreakyJoints: Psoriasis and Psoriatic Arthritis: What's the Connection?. February 2020.

<https://creakyjoints.org/living-with-arthritis/symptoms/psoriasis-and-psoriatic-arthritis-connection>

² Oliveira, M, et al. Psoriasis: Classical and Emerging Comorbidities. *Anais Brasileiros de Dermatologia*. February 2015. doi: <https://www.scielo.br/j/abd/a/BmtRNryvkSdwrV94Zsnn4Hh/?lang=en>

"When my plaque psoriasis was at its worst, I had large legions all over my body. I was forever shedding skin but I had no control over that and it was very embarrassing. When I tried to explain it to others, many still didn't understand. Some thought it was contagious or that I could treat it by using whatever concoction they had seen online. It was hard to know what advice to trust.

My legions weren't itchy but they looked awful, especially if they bled at the slightest scratch and didn't heal properly. I tried to cover them with clothing as much as I could but the friction from the fabric also irritated my skin. I couldn't hide the patches on my hands, face and scalp, though." — Steve A

Q2: How is the medical/health condition currently treated?

Treatment and access

Topical creams, ointments and courses of glucocorticoids are first-line forms of treatment for most people with active CPP. These can be prescribed by a GP.

Other treatments, such as light therapy and more advanced medications need to be prescribed by a dermatologist or dermatology registrar. However, there are only around 600 dermatologists in Australia and most of these practice in larger towns or cities. Therefore, people often need to wait many months just to get an initial appointment.

Getting to a dermatology clinic is a significant barrier for many, including those with mobility or transport limitations or those who cannot afford to see a specialist. People from regional or rural areas face additional barriers such as the cost of travel and accommodation and time away from work or their family.

"I saw a dermatologist many years ago. They prescribed light therapy but I didn't go as accessing one during working hours was challenging. The cost of seeing specialists, paying for prescription treatments and over the counter products all adds up. Trying new treatments is also a gamble. You don't know if they will work but you have to go through the trial and error process. Yet, how long do you wait to see if it helps or not?" — Steve A

Q3: What do you see as the advantages of this proposed medicine/change, in particular for those with the medical condition and/or family and carers?

We strongly support the sponsor's request for the PBAC to consider:

- Adding rheumatologists and general physicians as prescribers; and
- Allowing GPs to start patients on apremilast if they are experienced in the treatment of psoriasis or have consulted an experienced prescriber.

Rheumatologists and general physicians

We believe people who already see a rheumatologist or have easier access to a rheumatologist than a dermatologist should be able to see either specialist to increase their access to apremilast.

Rheumatologists are already highly experienced in diagnosing and treating psoriatic disease and related conditions so they are well-placed to assess the needs of CPP patients.

It would also be very beneficial for patients with both psoriatic arthritis and CPP to see a rheumatologist for both conditions. This would allow them to be treated more holistically and save them time and money.

"I was in a clinical trial for a psoriasis treatment and that gave me access to rheumatologists and dermatologists. It made sense for them to work together as their specialties complement and overlap each other. That medicine helped both my psoriasis and my psoriatic arthritis but it was only listed on the PBS for psoriatic arthritis. Luckily, that meant my rheumatologist could continue to prescribe it for me and I didn't have to see a dermatologist for a psoriasis treatment as well.

Allowing apremilast to be prescribed by dermatologists and rheumatologists seems logical to me, especially for people that have both psoriasis and psoriatic arthritis. Why see two specialists when one can help you with both conditions?" — Steve A

Sometimes, symptoms of psoriatic disease can resemble those of other conditions. General physicians specialise in diagnosing and treating people with difficult, serious or unusual medical problems (usually in hospital settings). Therefore, they may see the connection between a patient's seemingly unrelated symptoms, such as fatigue, skin lesions and swollen joints and diagnose psoriasis, psoriatic arthritis or both. When they do diagnose psoriasis, it makes sense for them to have the authority to prescribe the PDE4 inhibitor apremilast as a first line treatment when appropriate.

GPs

The PBAC has already agreed that GPs can prescribe apremilast for eligible people with CPP if a dermatologist or dermatology registrar has initiated this treatment course. This has benefited patients by allowing them access to a targeted oral medicine that can help calm their symptoms when topical treatments aren't enough and methotrexate is not an option. It also gives more treatment options to those who do not qualify for biologic treatments.

Accessing this treatment via a GP has also helped those with CCP as they don't need to pay to see a specialist or have regular blood tests. GPs are generally easier for people to access than dermatology professionals, rheumatologists and general physicians. Once again, this is especially so for those who have difficulty accessing specialist care due to distance, mobility issues or very tight budgets.

If GPs can diagnose CPP they can start patients on apremilast straight away. This could prevent the patient's symptoms from becoming more severe while waiting for a specialist appointment.

Expanding access to apremilast will also benefit the government as it is likely to delay or even prevent the need for some patients to progress to biologic medications — saving the government hundreds of dollars per prescription.

Perhaps more importantly, giving more patients a chance of significantly improved CPP symptoms will decrease their need to rely on the health system for related treatment, such as pain or mental health management and increase their productivity and quality of life.

Q4: What do you see as the main disadvantages of this proposed medicine/change?

One of the proposed access changes is to allow GPs to start patients on apremilast "if they are experienced in the treatment of psoriasis". However, it does not specify the level or type of appropriate experience or who would determine if the GP has enough experience to initiate treatment. Is it possible a GP might believe they have suitable experience (even if this was minimal) and therefore would not need to consult another doctor before starting someone on apremilast?

If so, then would there be a risk of inappropriate prescribing/dosing or lack of awareness of things like side effects or contraindications? We understand there may be protocols already in place to prevent such outcomes that we are not aware of so we will leave it to the PBAC to decide if this concern is valid.

Q5: Please provide any additional comments you would like the PBAC to consider.

N/a

Q6: If you have any suggestions on ways to improve this survey, please provide these below.

It would be helpful to have the option to provide input for more than one medicine in a single submission. This would be especially beneficial in cases where similar amendments are proposed for multiple medicines in one disease area.