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Global Healthy Living Foundation Australia and CreakyJoints Australia

Submission to support the listing of Deucravacitinib (Sotyktu®) on the PBS for the treatment of severe chronic plaque psoriasis

For consideration at the November 2022 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.

Our community members are mostly people with chronic health conditions, including patients suffering from chronic plaque psoriasis. Our comments include insights from an organisational perspective as well as detailed responses from Uli Eichhorn (a patient living with chronic plaque psoriasis) which encapsulates the lived experience of patients living with this condition.

Contact details

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Q3 I am providing this input on behalf of a consumer group/organisation

Q4 CreakyJoints Australia and our parent organisation Global Healthy Living Foundation Australia

Q5 My phone number is 0400 447 624

Q6 I live in Victoria

Q7 The medicine we would like to provide input on is **deucravacitinib** (Sotyktu®) for plaque psoriasis

Q8 We learned about this consultation via an email from [Patient Voice Initiative](#)

PBAC public consultation survey

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

CreakyJoints Australia/GHLF Australia

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 proven* that effective treatment won't just clear the skin but may also help patients lower their chances of developing associated conditions.

* 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>

Uli Eichhorn

- I've had CPP for 45 years (since onset at age 10). Seven years ago, I was also diagnosed with psoriatic arthritis, which has since caused significant pain and damage to my cervical spine.
- Over the decades, the state of my skin has significantly impacted my mental health and has contributed to medically diagnosed anxiety, depression and body image problems. Although I'm now in my mid-fifties, I still lack confidence.
- I experienced ridicule and bullying — especially when I was a child, teenager and young woman of dating age — because of the state of my skin and the constant flaking of my scalp. There's this massive 'yuck-factor' one has to deal with.
- I have tried so many different topical and systemic approaches but have not found anything that gives me significant relief from the CPP other than taking long and very expensive holidays in specialised treatment centres at the Dead Sea in Israel/Jordan.
- The itchiness often drives me insane.
- I would theoretically qualify for biologics, however, because I have had transverse myelitis (a demyelinating disease) since I was 3 years old, biologics aren't an option for me. I was always so hopeful that one day I would qualify, and now a whole range of options are out of reach for me. On bad days I struggle very much with this outlook. I feel deep sadness due to the hopelessness of my condition.

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

CreakyJoints Australia/GHLF Australia

Topical creams, ointments and courses of glucocorticoids are standard forms of treatment for most people with active CPP. The out-of-pocket cost of these over years or decades can have a large and negative effect on patients' finances. Yet, in most cases, patients have little choice but to keep using them to maintain some sort of relief from their symptoms.

UV light therapies are also a form of therapy used for CPP, but many people, especially those from regional or rural areas, have trouble getting to clinics where these treatments are offered.

Uli Eichhorn

- I'm currently on leflunomide, which is causing me massive hair loss. I'm not sure how long I can be on it. It's giving me relief from my psoriatic arthritis; however, it has zero effect on the CPP. Losing your hair is bad enough, especially for a woman. But losing your hair while your scalp is absolutely covered in psoriasis is just another level I don't know how to deal with.

- I use over-the-counter creams as well as Eleuphrat to de-scale my scalp, which is nasty business! I also use Enstilar topically for the rest of the body, but this only helps with immediate itchiness if the skin is too angry. I cannot get spots to disappear using these medicines alone. I'm very grateful for steroid creams, but I try to not use them too often because one always has to pay with a massive rebound effect.
- My dermatologist ruled out further UVB treatment because I already had so much of it throughout my life.
- I still expose myself to sunlight as much as possible, as sun and saltwater are the only things that give my skin some relief. Of course, I'm aware of the cancer risk, but what else can I do?

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

CreakyJoints Australia/GHLF Australia

To date, there are only four PBS-subsidised non-biologic medicines available for CPP. While these work well for many, there are still other patients who can't use them. This may be because they reacted to the medicine, it didn't work for them, or it was contraindicated for them. The problem is compounded if they do not qualify for biologic therapies. Therefore, we believe it is vital for more novel, non-biologic treatments to be made available through the PBS.

We see deucravacitinib as being advantageous for patients in several ways:

- It uses a novel treatment pathway, so those who have not had strong or sustained improvement from other non-biologic treatments will have a new option to try and the clinical trial results look promising.
- It is an oral treatment, so those with severe CPP who are uncomfortable with the idea of trying injectable treatments still have an option to try before progressing to biologics.
- It is proposed that the eligibility criteria and prescribing pathways for deucravacitinib via the PBS will be the same as for apremilast. Therefore, patients will be able to get a prescription from their GP, as opposed to waiting to see a specialist to get a biologic prescription.

Making deucravacitinib available through the PBS 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.

Uli Eichhorn

- Not only speaking for myself but also for all those others suffering from this dreadful condition, hope is often the only thing that keeps us going.
- I can honestly say that if there was a medicine that could improve (or even remove!) my CPP, it would be life-changing! I don't have words to express what this would mean to me after 45 years of constant suffering.

- Having access to a new form of non-biologic treatment would help me immensely. I can't stress this enough. My treatment options now are so limited! Methotrexate did nothing for me other than give me side effects, and I'm unsure how much longer I can be on leflunomide.
- I want to speak to my rheumatologist about JAK/TYK2 inhibitors. So far, I'm unclear if these are an option for me because I have demyelinating disease.

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

CreakyJoints Australia/GHLF Australia

We see no disadvantages to making deucravacitinib available through the PBS.

Uli Eichhorn

- Given the above, and my limited knowledge about this particular medicine, I don't see a disadvantage at the moment. My only worry would be that I might not qualify due to my transverse myelitis.

Q5: We are considering revising the consultation survey for future PBAC consultation rounds, along with providing additional guidance. Are there any suggestions you would like us to consider as part of this process?

CreakyJoints Australia/GHLF Australia

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.