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Global Healthy Living Foundation Australia and CreakyJoints Australia

Submission to support the expanded listing of anifrolumab (Saphnelo®) on the PBS for the treatment of severe systemic lupus erythematosus

For consideration at the March 2024 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 autoimmune conditions and biologics

Although our Australian team has not had much direct experience with systemic lupus erythematosus (SLE) and SLE patients to date, our colleagues at [CreakyJoints US](#) certainly have so we can draw on their collective knowledge as needed. What we do have is many years of direct experience with autoimmune arthritis and biologics through the lived experience of our team members and patient community.

We know what it's like to have multiple symptoms at the same time such as persistent fatigue, joint pain and stiffness, brain fog, depression and anxiety. We can relate to the frustration caused by delays to diagnosis, misdiagnosis, delays to treatment and the fear of what the future will bring.

We also understand that the severity of autoimmune conditions can vary from mild to extreme and that symptoms, comorbidities and responses to treatment are different for everyone.

A major difference between common forms of autoimmune conditions and SLE is the range of treatment options available to those with severe disease. Australians with severe cases of conditions like rheumatoid arthritis or psoriasis have had access to biologic DMARDs for many years as advanced treatments and these have been game-changers for many thousands of people. However, our friends with SLE have not been so lucky.

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

Like autoimmune arthritis, SLE is treated with a combination of medicines, including:

- Analgesics such as paracetamol or ibuprofen.
- Non-steroidal anti-inflammatory medications (NSAIDs) such as celecoxib or naproxen.
- Corticosteroids such as prednisolone or prednisone.
- Antimalarials such as hydroxychloroquine.
- Immunosuppressants, including disease-modifying antirheumatic drugs (DMARDs) such as methotrexate or cyclophosphamide.
- Lifestyle strategies such as pacing, exercise and avoiding stress.

These treatments are often enough to help those who have mild to moderate cases of SLE manage or even stop their symptoms. Immunosuppressants can also help to prevent disease progression for those in this cohort.

However, for many people with SLE, these treatments are simply not enough to keep their symptoms manageable. When symptoms like pain and rashes are not well-controlled, quality of life is often adversely affected. That can lead to a reduced capacity to work, study, enjoy relationships or simply have fun.

There are currently two biologic DMARDs that have TGA approval for prescription for SLE in Australia. However, we believe the uptake of these must be minimal as they are not subsidised through the PBS. While we do not know their retail price, based on the unsubsidised cost of other biologic medicines, we estimate they could cost users between \$800 and \$1,500 or more per month. That makes them unaffordable for all but a select few.

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 understand it is difficult to create a treatment capable of improving the many diverse symptoms of SLE. Therefore anifrolumab (Saphnelo®) may not treat the majority of SLE symptoms for the majority of people with this condition in Australia. However, we believe it is essential that anifrolumab is listed on the PBS as it has a good chance of helping some of the people who urgently need it. These people deserve the same access to biologics as those with severe forms of other autoimmune conditions have enjoyed for years.

We asked members of our CreakyJoints Australia community to share how biologics have positively affected their lives and why they believe those with severe SLE deserve the same level of access. The following comments sum up our arguments.

“I am a Crohn's disease patient and I know for many people suffering from this disease that biologics help give people their life back. Biologics work extremely well. Helping these people means they can help or work out in the community by either volunteering or paid work. This is extremely beneficial to our country and those involved. It is very important to give those with severe SLE access to biologics to help them live a healthy and enjoyable life.” — Donna M

“I am a sufferer of psoriatic arthritis, a disabling autoimmune disease. I rely on the use of a biological DMARD as part of my treatment to help me continue to have a good quality of life.

I am fortunate enough to be on one that is currently covered by the PBS, secukinumab (Cosentyx®). Had it not been covered I doubt I would have been able to use it due to the high costs involved, therefore denying my chance at better health.

I therefore support the addition of anifrolumab (Saphnelo®) to the PBS. This will allow fellow autoimmune sufferers, those with SLE, to also have this vital opportunity to be on a much-needed medicine that will greatly improve their quality of life at an obtainable price.” — Cheryl R

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

We can only see two disadvantages to this medicine. One is its cost to the government. We know that it may not be cost-effective to subsidise due to the relatively low number of people who stand to benefit. However, we firmly believe the Australian Government has the ethical responsibility to subsidise anifrolumab for those who will benefit from it. They deserve the same access to treatment as their peers.

The other disadvantage is nothing to do with anifrolumab itself. We believe it will help many people with SLE to some degree, but it's not enough. We need a good range of biologics for SLE with different modes of action as no medication can be a “one size fits all”. What works for one person may not work for another.

Also, for the few who can afford to pay for a private script of anifrolumab, there is no guarantee that it will work well for them forever. All biologics can cease to be effective for individuals over time so we need to have alternative options available when that happens.

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

We have no further comments to add.

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

We have no suggestions at this time.