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## Global Healthy Living Foundation Australia and CreakyJoints Australia

Submission to support the listing of tofacitinib 11mg extended-release tablet (Xeljanz® XR) on the PBS under the same conditions as the existing listings of tofacitinib 5mg for the treatment of severe active rheumatoid arthritis and severe psoriatic arthritis.

### ***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.

### Contact details

**Q1** Rosemary Ainley

**Q2** [rainley@creakyjoints.org.au](mailto:rainley@creakyjoints.org.au)

**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 **tofacitinib** (Xeljanz® XR) for severe rheumatoid arthritis and severe psoriatic arthritis.

**Q8** We learned about this consultation via an email from [subscription@pbs.gov.au](mailto:subscription@pbs.gov.au)

### 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 rheumatoid arthritis, psoriatic arthritis and tofacitinib*

As rheumatoid arthritis (RA) and psoriatic arthritis (PsA) are two of the most common forms of autoimmune arthritis they are also two of the most common conditions in our patient community. Also, two members of our CreakyJoints Australia team live with rheumatoid arthritis. Both are on biologics and one has tried tofacitinib 5mg.

Our websites are full of content and resources to help people with these conditions better manage their conditions, understand their treatment options and navigate the Australian healthcare system. We also regularly advocate for new medicines or expanded access to existing medications to be listed on the PBS.

Here are some examples of our work.

- [Medicinal and Non-Medicinal Arthritis Treatments](#)
- [Patient PrepRheum podcast](#)
- [A Patient's Guide to Living with Rheumatoid Arthritis in Australia](#)
- [My journey with psoriasis, psoriatic arthritis and peer support](#)
- [Xeljanz® Now Available on PBS for Those With Psoriatic Arthritis](#)

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

In Australia, people with RA and PsA have access to many treatments including disease-modifying anti-rheumatic drugs (DMARDs). Those with mild to moderate symptoms can access conventional synthetic DMARDs (csDMARDs), such as methotrexate, which work by suppressing immune system activity throughout the body. These can be taken with or without other treatments such as anti-inflammatories and analgesics. Most of these medications are taken in oral form, although methotrexate can be injected.

People with more severe forms of RA and PsA may qualify for advanced DMARDs that target specific parts of the immune system connected with one or more forms of autoimmune arthritis.

There are two categories of advanced DMARDs currently subsidised through the PBS — biologic DMARDs (biologics or bDMARDs) and targeted synthetic DMARDs (tsDMARDs). Biologics are injected or infused into the body (therefore bypassing the digestive system) while tsDMARDs are taken orally.

Tofacitinib is a type of medication called a JAK inhibitor — a sub-classification of tsDMARDs. It works by targeting JAK1 and JAK3 enzymes in the immune system and this inhibits inflammatory activity.

Currently, there are only two tsDMARDs subsidised by the PBS for psoriatic arthritis (tofacitinib and upadacitinib) and three for rheumatoid arthritis (tofacitinib, upadacitinib and baricitinib).

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

Many people find taking tablets is easier and less time-consuming than self-injecting biologics or having them injected or infused by a health professional. Also, many people don't like using needles to administer medication and biologics require a bit of training and practice to use properly. That makes JAK inhibitors an appealing treatment option for those with severe RA or PsA therefore increasing the likelihood of treatment adherence.

Tofacitinib 5mg tablets have been available through the PBS for several years and users take two tablets per day (one in the morning and one at night). We already know it is very effective for people with severe forms of RA and PsA.

This submission calls for the listing of tofacitinib 11mg extended-release tablet (Xeljanz® XR) on the PBS under the same conditions as the existing listings of tofacitinib 5mg. We understand the reason this once-a-day tablet is 11mg rather than 10mg is due to the manufacturing process and a little more is needed for it to be comparable with two doses of 5mg tablets per day.

The big advantage of taking a single 11mg tablet per day is that the active ingredient is released slowly and the concentration peaks after around four hours. By comparison, the 5mg tablet has peak concentration immediately then drops until the second tablet is taken. The two dosages have the same concentration in the body after 24 hours.

This indicates to us that a person using the 11mg dose would probably have less variation in their symptom levels over the course of the day than they would if they took two 5mg tablets a day. While this difference may not seem significant to some, the 11mg extended-release dose could enable the person to better manage their symptoms and achieve more throughout the day.

Finally, halving the number of tablets taken a day means the extended-release version uses half the amount of packaging per day. This means suppliers and users need less space to store the product, emissions from the manufacturing and transport processes are reduced and less waste ends up in the environment. That is a big win for everyone.

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

We are not aware of any disadvantages of extended release tofacitinib.

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

We have no additional comments to make.

### Q6: 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?

We have no suggestions to share.