



## **PBAC Consumer Submission for Ultomiris® Ravulizumab for MG patients** **Make your submission and have your voice heard!**

The Pharmaceutical Benefits Advisory Committee (PBAC) will assess a new treatment called *Ultomiris*® (Ravulizumab) for generalised Myasthenia Gravis patients at its [meeting in March 2024](#). The Myasthenia Alliance Australia (MAA) encourages MG patients and your carers or families/friends to **consider making a personal submission highlighting your lived experience**.

A PBAC submission is about getting this treatment at an affordable and therefore an accessible price. It is already approved by the Therapeutic Goods Administration (TGA) for use but is extremely expensive, so PBAC funding is the key.

**The MAA will make a submission on your behalf as the organisation representing all MG patients.** Individual and personal submissions help demonstrate the diversity of our experience with MG and the importance of having different treatment options to give us the best care and quality of life. We appreciate this may mean you have to think about some tough or difficult times and experiences, so please allow yourself space to do this or talk to someone about it.

The MAA believes this is an important opportunity to share our voice and lived experience with national decision makers. It is also an exciting time for new treatment options for MG and we want to ensure that these are **available, accessible, and affordable**. This aligns with Priority 2.4 of the [National Strategic Action Plan for Rare Diseases](#): Enable all Australians to have equitable access to the best available health technology.

**Who:** Myasthenia Gravis patients (and their carers or families/friends) can make a consumer submission to contribute to the PBAC evaluation of a new treatment: *Ultomiris*® (Ravulizumab). PBAC is the regulatory body that recommends new medicines for listing on the Pharmaceutical Benefits Scheme (PBS) based on medical conditions, clinical effectiveness, safety, and cost-effectiveness.

**What:** We are in the midst of an exciting time for new treatments for MG. *Ultomiris*® (Ravulizumab) is a long-acting complement C-5 inhibitor treatment with demonstrated statistically significant improvements in Myasthenia.

**When:** You can make a submission until **Wednesday, 31 January 2024**.

**How:** You can complete the **online form** [here](#). If you have issues with using the online form, you can **send an email** directly to [commentsPBAC@health.gov.au](mailto:commentsPBAC@health.gov.au). There are 5 questions to guide your response covering your experience living with MG, current treatments, and the potential advantages and disadvantages of the new treatment.



**Why:** Because **the patient voice matters**. Our involvement in these assessment processes “ensures that the advice provided is informed by the needs of the people living with health conditions” ([Conversations for Change Report](#), 2023, p.1). This is also taking action on our other key theme “**Nothing about us without us**”.

### **What can you do? Why should you consider making a submission?**

You don't have to have had or tried using Ravulizumab. Our submissions ensure that our voice and lived experience is part of the process. They should not only describe the symptoms, current treatments and side effects, but also our unmet needs with current treatments, the outcomes that matter most to us as patients for any treatment, and the desired benefits of this treatment and how its advantages might make a difference in our lives. Please include specific examples where you can.

A reminder that the MAA will make a submission as the national organisation representing and advocating for MG patients. Your individual submission will add to this by presenting your unique experiences and concerns living with MG. If you feel comfortable, please copy the MAA on your submission (you can send us the email copy you receive once submitted): [info@mgaq.org.au](mailto:info@mgaq.org.au).

We will send a couple of reminder notices about this opportunity throughout January 2024.

Kind regards,  
Susan White (MAA Chairperson)  
Natalie Windle (MAA Secretary & MGNSW President)  
Carol Buchanan (MGAQ President)

**More information and tips** about making a PBAC submission can be found through the Rare Voices Australia (RVA) and Patient Voice Initiative (PVI) websites:

<https://rarevoices.org.au>

<https://www.patientvoiceinitiative.org> and

<https://www.patientvoicehub.org/training/index.cfm?event=page.login>

**Please note:** Where the questionnaire asks you about **PERSONAL CONFLICT OF INTEREST**, this does **NOT** detract from your submission but ensures an understanding of the context of your views as part of a fair and transparent assessment process.