LUNG FOUNDATION
AUSTRALIA
*"When you can't breathe...
nothing else matters"™*

To the Chair of the PBAC

Lung Foundation Australia response to Draft Terms of Reference for BPS Post-Market Review on pulmonary Arterial Hypertension (PAH) medicines

Lung Foundation Australia (LFA) is a national not-for-profit organisation whose vision is to make lung health a priority for all in Australia. To achieve this, we promote lung health in the community; raise awareness of lung disease and symptoms of lung disease to facilitate early diagnosis; support those with lung disease and their carers; advocate for equitable access to evidence-based treatment for those with lung disease; and support research.

The Lung Foundation has a new and developing program for those with Pulmonary Arterial Hypertension. The objectives of this program:

- Raise awareness of symptoms of PAH in the community to facilitate earlier diagnosis. Symptoms of PAH are similar to other lung diseases and, as a result, confirming a diagnosis of PAH can be delayed, thus delaying access to medication.
- Provide access to evidence-based and credible advice to those with PAH and their carers to support patients to understand their disease and take an active role in managing it
- Promote equitable access to evidence-based treatment of PAH

LFA welcomes the PBS post-market review of PAH medications. While a rare condition, its impact on those with the disease is significant. As PAH progresses, the symptoms become more noticeable and debilitating. Breathlessness and fatigue become more a part of daily life, so that even simple tasks, such as getting dressed and walking short distances, become increasingly difficult. Fluids can build up in the legs and chest pain may also be experienced. As the disease worsens, patients become increasingly isolated.

The Lung Foundation works in collaboration with the Pulmonary Hypertension Society of Australia and New Zealand and would like to lend its support to the submission lodged by PHSANZ commenting on the proposed Terms of Reference.

In particular, the Lung Foundation as a patient body, advocates that ***priority*** consideration is placed on improving patient outcomes and supporting a funding regime that reflects the international guidelines for PAH, including early access to therapy for patients in Functional Class II and early use of combination therapy for those patients who continue to be in a higher risk category. This reflects practice in other publicly funded health systems in Europe and North America. For patients, early access to combination therapy can achieve that which is most important to most: improved functional status, reduction in symptoms and improved quality of life.

While cost-effectiveness is, of course, important to consider, this should be considered through a wide patient lens, including potential gains in QoL, productivity, impact on carers, social connectedness, etc.

Evidence has shown that patients' outcomes are improved when they are managed by experienced clinicians with a specialist interest in PAH. The TOR should also take in to account the current system of prescribing centres. Consideration should be given to the appropriate number of centres for Australia, taking into account population and geography. Consideration should also be given to what constitutes a prescribing centre, and who at the prescribing centre constitutes a recognised prescriber, should all be addressed in the TOR.

Thank you for the opportunity to comment.

Yours truly,

[redacted]

Heather Allan
Chief Executive

Cc: A/Prof Ken Whyte, PHSANZ President