PHA AUSTRALIA INC.
ABN: 86 815 330 924

TOGETHER WE ARE STRONGER

TO THE PAH REVIEW SECRETARIAT:

Pulmonary Hypertension Association Australia (PHA Australia) is an incorporated, registered, non-profit organisation, managed by an elected committee of 9. Our main objective is to provide support, education, create awareness and provide the latest information and research on all categories of Pulmonary Hypertension (PH) to our members and the community. Pulmonary Arterial Hypertension (PAH) is one category of PH. We have several thousand members across all media platforms made up of patients, carers and family members. Communication is via our secure website forums, our social media groups and our YouTube channel. PHA Australia works closely with the Pulmonary Hypertension Society of Australia and New Zealand (PHSANZ), the society of PH specialists and medical staff associated with PH, to ensure the best outcome for all affected by the disease.

Review Terms of Reference -

1. ***Review recent clinical guidelines for the management of PAH and compare this to the PBS restrictions and Therapeutic Goods Administration (TGA) indications for the use of PAH medicines.***

   Most patients would find the clinical guidelines for management of PAH way above their comprehension capacity. Our members, however find it difficult to understand why, in Australia, we don't have the same access to the range of drugs or the ability to have multiple PAH drugs at an affordable cost, as patients do in other countries. Our members rarely hear about clinical trials and would certainly take part in them if given the opportunity.

2. ***Review the utilisation of PAH medicines in Australia, including sources of data that can provide additional information on clinical use that is not available from PBS data.***

   PHA Australia is aware that a large proportion of our members are on combination treatment for their PAH. Unfortunately, exact figures are unavailable due to privacy constraints. Overseas studies appear to show that PAH related hospitalisation is reduced when multiple medications are applied which is good for both the patient and the health system.

Website: phaaustralia.com.au
Email: admin@phaaustralia.com.au
Facebook: pulmonary hypertension australia
Twitter: pha australia
YouTube: Pulmonary Hypertension Australia Inc. (PHAA)

Due to the current PBS restriction of only one PAH medicine being supplied patients must rely on hospital funding of drugs, compassionate supply by the drug companies or self-funding to enable access to additional treatments. Only those that are financially able can self-fund, many selling property or cashing in retirement savings to do so. These drugs are extremely expensive and the costs involved cause stress and anxiety among patients and their families as they fear their drugs may be cut at any time.

Many members across Australia are treated in large centres of excellence in major cities whilst others are treated in smaller centres regionally. Because PAH is a rare disease and difficult to diagnose it is critical that all patients, regardless of where they live, are offered the best possible care and treatment. To achieve this there needs to be a greater emphasis on linkage between the centres of excellence who see high numbers of patients in clinics that operate several days a week with very experienced doctors and the regional centres that see small numbers of patients with less experienced doctors and operate on a significantly less frequent basis. Many members travel long distances to the clinics that are centres of excellence, some travel interstate.

PHA Australia has the ability, through its members, to gathering data that may not be available to the PBS from other sources.

3. ***Review the clinical outcomes that are most important or clinically relevant to patients with PAH, and the extent to which these outcomes are included in the evidence previously considered by PBAC.***

Most studies have concentrated on assessing changes in exercise capacity. It is true that our members value exercise but equally they value how they feel, how they function day to day, and whether their treatment is going to keep them out of hospital and alive. Some members are acutely aware that if they end up in hospital it can signal that it sadly could be the start of the end of their time. Because PH is a rare disease, limited patient numbers are available in Australia and so it can be hard to conduct clinical trials here. Regional patients are essentially excluded due to the distances required to travel regularly to the trial centre in major cities. The financial burden on patients and families is a very large factor.

The recent change to the requirements for continuation of PBS supply of PAH medicines has been viewed as positive by our members. Members have always been anxious and stressed each time they go for their 6 monthly review and the critical emphasis placed on the 6 minute walk test result to ensure they continued medication. Recent approval of additional medications for PAH has been welcomed. The stress incurred when medication options are running out and the next step is unclear puts immense strain on patients and families. Currently we have 8 medications, Macitentan, Ambrisentan, Bosentan, Iloprost, Epoprostenol, Sildenafil, Tadalafil and Riociguat. Additional medications are currently being trialled or being submitted for PBAC review which gives the hope that we, in Australia, will have access to all PAH medications available in the USA and Europe. The addition of more medications will give hope to patients whose medication options are currently limited.

4. ***Collate and evaluate evidence on the comparative effectiveness of PAH medicines, including combination use and use in the WHO functional class II patient populations.***

It seems nonsensical that PAH medicines are only reimbursed for PAH that has come about for particular reasons. An example is PAH due to drugs and toxins, which to our knowledge, has no access to reimbursed treatment in Australia even though they are a relatively small group of patients. If a patient is lucky enough to be diagnosed as functional class II (very few) it doesn't make sense to have to wait until the disease worsens to class III before you have access to reimbursed medicines. PAH is PAH regardless of functional class and a small number of patients are discriminated against on the basis of how they got their disease and or how severe it is.

5. ***Following TOR 1-4 consider reviewing the cost-effectiveness of existing PBS listings for PAH medicines, and in treatment of WHO functional class II and combination treatment in class III and class IV patients.***

The cost-effectiveness of these medications needs to be assessed with regard to new patient outcome measures. Mortality should be a lesser outcome measure and the patients' ability to continue to live a productive life with quality should be substituted. It is well known and evident overseas that multiple medications and medications started as early as possible in the diagnosis of PAH, regardless of the class, is cost effective and reduces hospitalisation in most cases.

In conclusion all PH patients, regardless of what category they have, find the journey stressful and a financial burden. The emotional, psychological, and financial stress caused by PH impacts all patients and their families. This disease affects, on average, 18 members of the immediate and extended family and continues long after the patient has lost their battle with the disease.

Additionally, there also needs to be recognition of the disease across all government departments but most importantly in Centrelink. Members are frustrated that they need to jump through hoops and need to constantly educate consultants every time they apply for any benefits or need to make changes.

Joan Godber – President (Volunteer) on behalf of PHA Australia's Committee of Management

Annie Whitaker, Jason Mountstephen, Helena Pearson, Kevin Burke, Shayne Mifsud, Carmel Norton,

Mel Alexander, Brooke Norton