

The Unicorn Foundation Australia comment on *Medicines Australia Oncology Industry Taskforce Access to Cancer Medicines in Australia* Report

The Unicorn Foundation is grateful to have the opportunity to comment on this timely and important report from the perspective of a rare cancer stream – neuroendocrine cancer.

For decades the PBAC and PBS have executed their duties in an ethical and rigorously scientific manner so as to ensure that Australian cancer sufferers can access the most clinically appropriate and cost effective therapeutics.

Unfortunately, in the era of personalized medicine with greater scientific understanding of biogenetics, cellular modulation, signaling and adaptation the PBS listing process has been found to be cumbersome, costly, time consuming and for many desperate rare cancer sufferers – inequitable.

For uncommon cancer sufferers such as those with neuroendocrine cancer, they see the PBAC being unduly influenced by the powerful lobby groups and pharmaceutical companies that are interested in more common cancers. Rare cancer patients die earlier than those with more common cancers because of this bias. This has created a mistrust and cynicism of the PBAC and the PBS listing process.

We need to rebuild trust, improve transparency of listing processes, reduce the time for listings and get the medicine to the patient. This presents a significant challenge that urgently requires consultation between health consumers, pharmaceutical companies, government and the medical and scientific communities.

The Unicorn Foundation understands that significant issues need redressing in the process of reform, such as:

- Development of a single agency linking TGA, PBS, MSAC to coordinate assessment of therapeutic treatments and the associated diagnostic tests
- Improve transparency of the assessment process;
- Greater involvement of health consumers from rare cancer streams
- Development of regular forums to assist in the development of strategic goals that can help highlight priority areas of therapeutic needs in the Australian population
- Develop economical and efficient processes that allow for the expansion of TGA and PBS clinical indications for already approved drugs
- Reassess the economic cost/benefit ratios and quality of life instruments that are currently used to validate and compare drugs to take into account factors such as disease free progression and the psychosocial patient factors that may be more appropriate for rare cancer patients
- Development of a Government funded Rare Cancers Drug trust allowing patients access to drugs in a timely manner, outside the PBS listing process.



# Unicorn Foundation

*Seeking the cure for  
Neuroendocrine Cancers*

This reform process is a matter of extreme urgency as thousands of Australians are suffering physically, emotionally and financially due to delays in access of appropriate treatments and no where is this more apparent than in our patients who suffer from rare or uncommon cancers.

I congratulate Medicines Australia Oncology Taskforce for commissioning this report and hope that this provides the impetus for further discussion and reform in this new 'era' of personalized medicine.

Dr John Leyden  
Chairman, The Unicorn Foundation Australia

*The Unicorn Foundation is the only not for profit medical charity directed to raising awareness, education, patient support, advocacy and fundraising for research in Australia and New Zealand in the area of neuroendocrine cancers.*

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