# RECORD OF CONSUMER HEARINGS

## Consumer meeting with the Unicorn Foundation

The meeting covered the upcoming PBAC consideration of lanreotide for the treatment of patients with non-functional gastroenteropancreatic (GEP) neuroendocrine tumours (NETs). The November 2016 meeting will be the PBAC's second consideration of lanreotide for this condition. The following points provide a summary of the perspectives presented by the Unicorn Foundation to PBAC representatives:

- There are currently limited treatment options for patients with non-functional GEP-NETs. Patients want an active treatment option for this incurable, and often inoperable, cancer and patients perceive a "watch and wait" approach as being inadequate. Regular contact with a specialist and the additional monitoring associated with treatment with lanreotide was considered to be linked to psychosocial benefits for patients and their families.
- While the lack of a survival benefit associated with lanreotide (compared with placebo) was acknowledged, patients give substantial weight to the gain in progression free survival. There is a view that lanreotide treatment provides patients with reassurance associated with disease control and often reduction in the size of the tumours, and additional time, during which more effective treatments may become available.
- Patients consider lanreotide to be mostly well tolerated and that the potential benefits in slowing progression outweigh the side effects of lanreotide treatment. The convenient method of administration of lanreotide, as a monthly subcutaneous injection, was noted.
- Patients consider that it is inequitable for lanreotide to be listed on the PBS for functional carcinoid tumours but not non-functional tumours; subsidised access should not discriminate on the basis of symptoms, as symptoms are not necessarily indicative of the likely progression of tumours. There is a perception that some patients with non-functional GEP-NETs are currently receiving PBS-subsidised lanreotide through the functional carcinoid tumours listing, with potential differences in prescribing practices between clinicians, resulting in additional inequity within the non-functional GEP-NETs population. The Unicorn Foundation advised that these prescribing practices may affect the accuracy of current data collection which may confound future research into NETs.
- The Committee was advised that attempting to restrict PBS-subsidised lanreotide to a subgroup of non-functional GEP-NETs patients who are considered most likely to progress and become symptomatic would exacerbate the current issues and concerns of inequity of access. Accordingly, a PBS listing for all patients with non-functional GEP-NETs would be preferred by patients; prescribing of lanreotide would then be left to the judgement of the clinician.

## Consumer meeting with Rare Cancers Australia

The meeting covered the PBAC consideration of romidepsin for the treatment of patients with relapsed or refractory peripheral T-cell lymphoma (PTCL) and vorinostat for the treatment of patients with relapsed or refractory cutaneous T-cell lymphoma (CTCL). The November 2016 meeting was the PBAC's first consideration of romidepsin and second consideration of vorinostat for these conditions. The following points provide a summary of the perspectives presented by Rare Cancers Australia to PBAC representatives:

- There are currently limited treatment options for patients with relapsed or refractory PTCL and CTCL, and available treatment options have high toxicity.
- The physical manifestations of the condition have a profound effect on patients' quality of life. In particular the impact of ulcerated lesions associated with CTCL on patients, including lesion pain, frequent need for painful local treatment, and the cost of associated consumables (for instance bandages and dressings) were described.
- Romidepsin and vorinostat are offered to some patients currently, but (unless the patient is able to access treatment through a clinical trial) this is at a very high cost to the patient. Patients consider that this is inequitable.
- Patients consider romidepsin to be mostly well tolerated, noting that side effects had been transient, manageable, or able to be resolved with reduction of dose.