

30.8.2023

Committee Secretary  
Senate Standing Committees on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

To Committee Secretary

Submission letter for the senate enquiry: *Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer. It is this latter disease group in particular for which I have clinical experience.*

By way of background, I am a cancer specialist (Medical Oncologist and Nuclear Medicine Physician) involved in the management and support of patients with Neuroendocrine Cancer or Tumours (NETs). I am the Inaugural and current chair of the NET multidisciplinary tumour meeting which services South Australian and Northern Territory patients, and I am the clinical lead of the SA/NT Service which provides specialised care in the form of Peptide Receptor radionuclide therapy, or PRRT to patients with NETs.

Throughout the greater than 20 years of service to this most resilient and poorly understood patient group, I have- and continue- to bear witness to the consequences of limited awareness, missed diagnoses, ongoing restricted access to a range of core investigations, and the significant impact this has on the patient, family and extended network. Many of these patients are young and are working hard to raise families and stay well enough to remain in the workforce. Daily, they must contend with financial challenges of out of pocket expenses, reduced income as they navigate schedules that necessitate scans, treatment and surveillance. Their physical, emotional and social wellbeing is challenged at every turn.

The complex nature of this disease has necessitated that many specialised therapies be delivered in larger metropolitan health institutions, currently limited to 5 or 6 centres within mainland Australia. For our specific patient cohort within SA and NT, many patients travel 100's of kilometres, and it is a similar story for patients traversing the vast Western Australia, or Tasmanians

travelling to Melbourne. This removes them from their vital support network as they often find themselves alone when they are at their sickest and most vulnerable state.

I have personally been part of innumerable working groups, provided expert opinion for multiple submissions and been interviewed recently as a clinical expert for MSAC application 1744 for the funding of <sup>177</sup>Lutetium Octreotate). This latter application addresses limited access to, and funding for, a range of issues related to this group of patients, with molecular Imaging with Positron Emission Tomography (PET) being the most pressing issue. As a mandatory investigation, PET guides treatment at many time points (initial surgery, restaging, as a gateway to PRRT) with evidence confirming it is the most sensitive modality for surveillance and survivorship. Restriction in access and the lack of an equitable funding model continues to hinder ongoing clinical improvements that we all know are possible but continues to be denied or deferred.

Although there has been verbal support provided to advocacy groups and individual institutions time and time again, always supported by business cases and extensive health economic data, there has been a decided deficiency in dedicated funding to patients with NETs.

There will be many submissions that will be presented to the Senate for this current inquiry and they will be in the form of impassioned letters from patients and carers, health care workers writing as individuals, as well as formally executed documents from a range of organisations, to add to the already near insurmountable data and evidence.

The summary of all these will be the same. There are thousands of Australians living with neuroendocrine tumours. They are as deserving as anyone with a more common illness, of a funded pathway to ensure they live their best possible lives. This will reward family, friends and community, as well as the Nation as a whole, by enabling them to live with reduced disease burden, contribute financially (both by remaining in the workforce and not requiring additional benefits) as well as paying it forward as advocates and active participants in life.

I fully support this application and believe that the development of a contemporary, forward thinking funding model will ensure that not just patients with NETs, but the much wider group of patients living with rare and uncommon disease, can continue to live their best lives.

