



24 February 2017

Committee Secretary

Select Committee into Funding for Research into Cancers with Low Survival Rates

Department of the Senate

PO Box 6100

Canberra ACT 2600

Dear Sir/Madam

I write as a survivor of neuroendocrine tumours (NETs). I am one of the lucky ones, because in spite of having a 'differential diagnosis' which some specialists refused to investigate, I insisted on pursuing my non-conforming symptomatic status until I was correctly diagnosed and had life-saving surgery. Far too many people with NETs have symptoms which go unrecognised; have a diagnostic trail which is long, costly and frustrating; and, in part because of these time-lapses, have poor outcomes – or poorer outcomes than have come to be expected of folk with more common cancers.

In an era where there are potential pathways toward better outcomes for NET patients, it seems unacceptable that there are bureaucratic blockages in place to achieving these pathways.

In relation to Term of Reference (TOR) (a), it certainly appears to be the case that the capacity of organisations and individuals working on behalf of less-well-known-cancers (and those with low survival rates) to attract non-government funding is always likely to be less than those with higher profiles, greater degrees of organisational support, 'market' reach and the chance for more 'success stories'. Thus the current NHMRC model is always likely to work against the achievement of funding for those unable to attract substantial non-government funds.

In relation to TOR (b) there have been extended delays and often convoluted bureaucratic processes for NET patients and family members seeking to get a clinical trial funded. Clinical trials for certain NET patients and treatments have proceeded in some Australian jurisdictions. The achievement of equitable treatment across jurisdictions has involved extensive, and not necessarily successful lobbying of State and Commonwealth Ministers and Opposition members as well as bureaucratic decision-makers. NET patients and family members have, themselves, been involved in fundraising for clinical trials, perhaps at a critical time in their illness

when their human and financial resources might be required elsewhere. It seems clear that access to possible treatment is denied some patients as a result of obstacles to clinical trials. This may result in shortened lifespans for some. It certainly results in a loss of productivity for NET patients who may, with appropriate treatment, may be able to carry on working for longer. And that loss of productivity is compounded when family members' time and energy is diverted into extended 'caring' roles for patients who have had to retire earlier than expected from paid work or family responsibilities. I am reminded, that, some years ago, the cost of removing lead from petrol was considered prohibitive, until associated health and social costs were factored in – and the lead came out of petrol! Maybe, in this instance, the social and economic costs of removing obstacles to clinical trials need to be factored in - to society, and to families.

In relation to TOR (c), the possibilities of pathways to new treatments and increased survival rates through funded research into less-well-known-cancers (and those with currently low survival rates) are unknown. They are also enormously exciting and potentially enriching for the lives of those involved as well as for undreamed of scientific endeavour.

In relation to TOR (d) and following on from the above, sometimes 'taking a chance' on extending research funding beyond the popular/critical mass can also result in breakthroughs for mainstream research, or for unrelated medical conditions. Unquestionably, what such research funding also does is invest in the minds and talents of Australian medical researchers who may otherwise be tempted off-shore, to apply their skills and rigour to local issues and concerns. Such research should not preclude sharing of current information and knowledge (such as through open-source collaborations) but the political rhetoric of being smart and agile can start here!

Thank you for the opportunity to make this brief submission. I would be willing to speak to the submission if required. I certainly look forward to the Committee's deliberations and the outcomes of your inquiry.

Yours sincerely

Jacqueline (Jackie) Ohlin