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Dr Peter Murray Deputy Medical Director Pharmac PO Box 10254 WELLINGTON

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Pete,

Thanks for your email clarifying the nature of changes Pharmac has made under Special Authority with respect to the management of cancer medicines, in light of the current COVID-19 crisis.

You have asked if I have any ideas on this issue that I would like to put forward for consideration and indeed I do. They concern risks posed by aspects of the current treatment of patients with CLL, as follows.

1. A fellow Trustee of CLL Advocates NZ (CLLANZ), haematologist Gillian Corbett, has raised serious concern about the risks posed to patients in the administration of the current funded standard-of-care treatment for patients with del17p and relapsed refractory CLL. She has a patient starting treatment this week who had to go across town for urgent lab testing twice in one day, and again the following morning for tumour lysis syndrome (TLS) management. She noted that IV hydration needs to be considered in these patients, and that her patient will likely need to have more urgent blood tests during the coming week. She will need to have the procedure repeated next week. Gillian is very concerned about patients like this one having to put themselves at risk by going to the labs where there is likely to be a long wait, which in their immune-suppressed state would increase their risk of infection, including COVID-19.

For this reason we would like to propose that a change to CLL treatment be made under Special Authority to enable ibrutinib, which is taken in tablet form at home, to be funded temporarily for del17p and relapsed refractory CLL patients. In addition to being a home-based treatment, ibrutininb requires very little monitoring, infrequent blood tests and infrequent attendance at hospital (outpatients).

- We also propose that the Special Authority enables newly diagnosed fit and unfit patients to
 access ibrutinib, to avoid the need for chemotherapy or a delay in initial treatment. Again
 this would be a temporary SA to be in place until such time as patients can safely undergo inhospital care.
- 3. Finally we propose that the Special Authority for ibrutininb should also apply to treatment for CLL patients who are having intravenous therapy in a hospital setting, such as rituximab or obinutuzumab, which is given by infusion and requires, particularly initially, prolonged attendance at the chemotherapy department which is highly undesirable at this time of the COVID-19 epidemic.

As you would know, patients with CLL are immuno-compromised, and most are in the most at-risk age group, so we believe for all these reasons Pharmac should move quickly to make these changes.

I don't have an accurate understanding of the numbers of patients this would involve, and I'm currently canvasing CLLANZ subscribers for further input on this issue. But I understand there has been a significant drop in people presenting with CLL, no doubt due to the general pattern of people avoiding going to the doctor. The same may be true of RR patients. I understand that HSANZ may be looking at the likely number of patients who would benefit from these changes, but that the numbers involved are likely to be very small and the costs therefore low.

It seems to me, at a time when so much effort is going in to saving lives, implementing this proposal would be a most worthwhile contribution from Pharmac.

I'd be very happy to discuss this with you or provide any further information you may require, and look forward to hearing back from you on this request.

Kind regards

Neil Graham FRACP, FRCP

Executive Director

CLL Advocates NZ