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Emily Marschke, Technology Appraisal Project Manager, National Institute for Health and Clinical Excellence, MidCity Place, 71 High Holburn, London WC1V 6NA

18 October 2006

Dear Miss Marschke,

Re: Bortezomib for Multiple Myeloma

Thank you very much for the opportunity to comment on the Single Technology Appraisal (STA) Appraisal Consultation Document (ACD) that reviews the use of Bortezomib for Multiple Myeloma.

Overall we believe that the report by the Evidence Review Group – (ERG) - (Southampton Health Technology Assessment Centre – SHTAC) provides both a thorough and fair review of the available clinical evidence base.

However as a patient organisation we are obviously disappointed to see that the NICE appraisal committee failed to give positive guidance on the use of bortezomib for multiple myeloma. We fail to understand how the appraisal committee has reached a different conclusion to the British Committee on Standards in Haematology (BCSH) as demonstrated in their recent position statement having reviewed the same clinical evidence.

The lack of a truly effective treatment for patients at first relapse, and the failure of NICE to give positive guidance to bortezomib, could subject many myeloma patients to a premature death, or at the very least it will force patients into private healthcare where bortezomib is widely available leading to a two-tier health care system. Many patients may be forced to sell personal possessions in order to fund their treatment. This is clearly an unacceptable situation in the light of the ambitious and forward thinking ideals laid out in the Cancer Plan 2000, presented by Alan Milburn.

One of his key tenets was to ensure that England would no longer lag behind Europe in its approach to the treatment and care of patients with cancer, and to ensure equity of treatment notwithstanding the background or class of the person suffering from the disease – clearly this is not the way to do that!

In order to minimise the volume of appeals that the NICE Committee will have to review, I have submitted my appeal to this decision as a joint document with the International Myeloma Foundation, The Leukaemia Research Fund and cancerbackup.

I hope that the comments we make in our appeal document are helpful for the Appraisal Committee and would like to restate the fact that in its review of the evidence the ERG were very positive about the use of bortezomib in multiple myeloma.

Please do not hesitate to contact me if you require any further clarification or explanation of our feedback.

Yours sincerely

Anthony M Gavin Chief Executive Leukaemia CARE