Dear Mr Powell

Thank you for sending me the consultation documents for the appraisal of Alemtuzumab for relapsing-remitting multiple sclerosis. I'm afraid that despite the best efforts of both Stuart and Heidi I was unable to open the Evaluation report and so my comments are limited to the ACD itself – I hope that is alright. I have also spoken to the team at the MS Society who were kind enough to put me forward as their patient expert for this consultation, and find myself in full and enthusiastic agreement with their statement. Obviously their response is an extremely well-considered and professional response; I hope that this email is sufficient as the response of a patient to the Committee's decision.

I am hugely disappointed to hear of the initial decision of the Committee following a long meeting discussing the benefits of alemtuzumab to patients with RRMS. From a personal perspective as a person with relapsing-remitting multiple sclerosis who has received treatment with alemtuzumab I can attest to the huge benefit of treatment for my condition, allowing me to be in better health (physical and mental) six years following my last regime than I was at diagnosis or for the eighteen months following. At diagnosis my MS was both rapidly evolving with fresh symptoms occurring frequently, and highly active – and the difference treatment made has been huge. Alemtuzumab really does have significant positive effects on the disease, and they last for a significant length of time.

I believe that the Committee has been slightly mistaken in some of its conclusions. I fully understand the necessity of placing the majority of the focus for decision-making on the cost-effectiveness of a new treatment in order to make recommendations to the NHS – as a 'free at the point of delivery' service, the NHS must absolutely ensure that any drug it is allowed to use provides maximum patient benefit for as long as possible, with as few side-effects or harms as possible and for as low a cost as can be arranged – but I believe that in their initial decision the Committee have placed themselves in the difficult position of having to explain to the MS community (not only here but worldwide, in light of similar decisions being made globally) why the ability of a MS patient to choose a treatment has been curtailed. The newly revised NHS Charter outlines the rights of patients to be given choice in their treatments, and by not recommending alemtuzumab this choice is then limited to the currently existing drugs, many of which do not provide the long-term benefits or convenient treatment schedule of alemtuzumab. As people also tend to be diagnosed with active disease, then allowing the use of alemtuzumab as a first-line treatment would be the best possible outcome – treating the condition early in its progress and limiting the accumulation of disability from early relapses is paramount for continuing a normal life into the future.

If alemtuzumab is not licensed for use in the NHS, a situation of potential discrimination is also established. As the drug *has* been licensed by the European Medicines Agency then it is available for those with private healthcare arrangements, allowing those with the necessary finances to receive the drug while still continuing to exclude others who may need it. I appreciate that 'fairness' is not an economically valid argument, but as those who are diagnosed with MS go on to suffer from other economic penalties such as health-related early retirement, increased levels of unemployment and costs associated with care, improvements to living conditions etc it seems unduly harsh to add 'effective treatment only for those who can pay' to the list.

Having actually had treatment – having sat in a hospital bed with a cannula dripping alemtuzumab into a vein, having suffered from sweats, chills, rigours and rashes, and having gradually realised over the course of a few weeks post-treatment how well I felt, I think I can say that the Committee has also overstated the side-effects of treatment. As I explained in my initial patient expert statement, the treatment does indeed have some immediate adverse effects; however these take

place in hospital during treatment, and are easily treated at that point. None were bad enough in the first year of treatment to dissuade me from returning for a second year of treatment. The long-term side-effects, such as the development of other autoimmune conditions, can be spotted with the regular blood testing and if the patient is compliant, can be treated as they arise. I realised during the first meeting of the Committee that the list of side effects preyed heavily on people's minds, but there are few MSers I have spoken to who would find anything on that list more problematic than their existing condition. Again, it is about choice – people with MS need to be trusted to understand the cost-benefit ratio as it applies to their own experience of the condition. They know whether the disease or the treatment would be worse for them on an individual level, and must be allowed to make their choice – either way.

If the focus, of necessity, has to be on health economic grounds, then perhaps the true cost of the disease across a life-course needs to be explored, including periods of unemployment, social and care costs, other medications such as for depression and anxiety as well as the rippled-out costs and pressures on family and friends. The cost of the drug would be high if it didn't work so well and offer such long-term benefits, but set against the cost of treating relapses and deterioration in a patient, the cost seems reasonable to those of us who live with the condition. As there are so few effective treatments for MS currently available, it is surely necessary to licence a new one that could benefit so many more patients, especially if given as a first-line treatment to protect against early disability accumulation.

I will be attending the second Committee meeting on 21st January and look forward to following proceedings again. Thank you for your help
Best wishes
Helen Burchmore