Catherine McKinnell MP

HOUSE OF COMMONS
LONDON SW1A 0AA

Sir Andrew Dillon
Chief Executive
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London WC1V 6NA

16 AUG 2011

Our ref: NN3679/AB

10 August 2011

Dear Sir Andrew,

**Multiple sclerosis (relapsing-remitting) – Fingolimod**

I write to express my concern that the National Institute for Health and Clinical Excellence (NICE) has recently published draft guidance indicating that Fingolimod (also known as Gilenya) should not be approved by NICE for the treatment of relapsing remitting Multiple Sclerosis (MS), on the grounds that it is not cost effective. I would be most grateful if this letter could be considered as part of the ongoing public consultation on this issue.

Fingolimod/Gilenya has been licensed by the Medicines and Healthcare Regulatory Authority (MHRA) as a safe and effective oral treatment for people who have highly active relapsing remitting MS, and who have failed to respond to injection treatments, or for those with rapidly evolving severe MS – thereby meeting a clear, unmet medical need. I am therefore very concerned that a final NICE decision not to approve this medication would leave some people with MS unable to access an effective treatment option, thus exacerbating both the 'postcode lottery' of MS treatment that already exists in this country and the relatively poor approach taken by the UK to MS care when compared with other European countries. As you may know, a recent report by Prof. Sir Mike Richards indicated that the UK is ranked 13th out of 14 countries in terms of access to new treatments for MS, and I am concerned that a negative final NICE decision on Fingolimod/Gilenya will only widen this gap further.

I am equally concerned that the NICE draft guidance does not appear to take into consideration the wider social and economic benefits of treatments like Fingolimod/Gilenya, which – by reducing the number of relapses and delaying disability progression – will enable people with MS to remain in work, and therefore not dependent on state support, for longer. This again is an area in which the UK currently lags behind other European countries, with 44% of people with MS in the UK currently retiring early as a result of their condition, compared with a European average of 35%. This must surely be taken into consideration when appraising the overall cost effectiveness of a treatment.

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Finally, I understand that NICE reached its draft decision on the cost effectiveness of Fingolimod/Gilenya by comparing it to 'best supportive care', that is care where MS patients take no medicine for their condition. It is difficult to understand how any new treatment will be assessed as cost effective when measured against no treatment, and I would therefore urge you to ensure that this method of assessing treatments is reconsidered.

Yours sincerely

Catherine McKinnell

**Catherine McKinnell MP**
**Chair, All-Party Parliamentary Group on Multiple Sclerosis**

Working hard for Newcastle North

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