

7 March 2012 Attention Kate Moore Technology Appraisal Project Manager

Dear Ms Moore

Re Appraisal consultation document related to the Single Technology Appraisal STA for Botulinum Toxin A (Botox) in the prevention of headache associated with Chronic Migraine (CM).

I am submitting the response below on behalf of The Migraine Trust.

a) Has all of the relevant evidence been taken into account?

The Migraine Trust takes the view that not enough weight has been given to the benefits that patients experience when being treated by Botulinum Toxin A (Botox). Patients who have benefitted have already failed to respond to at least 3 other treatments and the options left to them are less desirable, with often intolerable side effects and indeed more expensive.

The disabling nature of Chronic Migraine means that any reduction in the severity of symptoms can make an enormous difference to the patient's ability to function and to their general quality of life.

Botox may help return a patient's migraines to the episodic state where other treatments become available to them and are therefore able to avoid the devastating impact that CM has on family relationships, ability to work and quality of life.

b) Are the summaries of clinical and cost effectiveness reasonable interpretations of the evidence?

NICE has looked at the cost of an episode of treatment with Botox in the NHS but has not, in our view, given enough emphasis to the fact that patients with CM have repeated referrals to the NHS due to the nature of their condition.



There seems to be an assumption that no treatment means no cost but there is a cost in that patients who are not getting relief will take up more time within the NHS.

The cost of treatment would reduce with specialist headache nurses administering the treatment. The Migraine Trust organised a training day for specialist headache nurses on treating CM with Botox and I can say from personal experience that they are well placed to fulfill this role.

Research has shown that people with CM move back to episodic migraine in the same proportions as those who move into it which suggests that patients would not be likely to need continuous treatment with Botox to treat CM. (Bigal M E, Lipton E; 'The chronification of headache' Headache January 2008 pp7-15)

c) Are the provisional recommendations sound and a suitable basis for guidance to the NHS?

The Migraine Trust is disappointed that NICE was not able to recommend Botox. This is the last hope for a number of people and the only licensed treatment available. The only other preventative with evidence is Topiramate which as an anti epileptic drug has obvious limitations for a patient population which is predominantly young and female.

d) Are there any aspects of the recommendations that need particular consideration to ensure we avoid unlawful discrimination against any group of people on the grounds of gender, race, disability, age, sexual orientation, religion or belief?

CH is common in younger women so there needs to be due consideration to this group.

Migraine, although not specifically mentioned by name, can be classed as a disability when the patient with the condition meets the criteria of disability in The Equality Act 2010.

e) Are there any equality-related issues that need special consideration and are not covered in the ACD.

As above in d). If people with CM are forced to go privately, then women are doubly disadvantage by earning on average less than 15% than men.

Yours sincerely

