

Peter Clarke

Chair Appraisal Committee

5th March 2012

Dear Sirs

Botulinum toxin type A for the prevention of headaches in adults with chronic migraine.

Migraine Action is the main patient interest national charity in headache in the UK. We aim to bridge the gap between people affected by migraine and the medical world by providing unbiased information on all aspects of migraine and to raise awareness about the realities of living with migraine amongst the general public. Migraine Action offers support and advice via a telephone helpline, numerous leaflets on all aspects of migraine, an informative website, a members' newsletter and access to a specialist nurse telephone helpline service. Migraine Action also helps to reduce the isolation that migraine can cause by putting members in touch with other people affected.

The World Health Organisation ranks migraine as the 19th most disabling disease. Women are three times as likely as men to suffer from migraines, which are also linked to depression and anxiety, of which the cost to the NHS and the economy runs into billions of pounds per year. This condition can greatly affect all aspects of life - family, work, and social life.

Migraine Action is extremely concerned that should, what is the only licensed Chronic Migraine treatment, Botulinum Toxin, not be made available to patients, an opportunity would be lost to reduce further patient suffering.

Key findings of recent online survey of 97 patients with Chronic Migraine:

13.4% of participants had tried Botox to manage their chronic migraine.

Interestingly 48.5% would like to try Botox to manage their chronic migraine suggesting lack of control from current treatment but as yet could not access the new option.

Supporting migraineurs and their families

Raising general awareness

Supporting specialist migraine clinics

Research and investigation: causes, diagnosis, prevention and treatment

Facilitating the exchange of information

Migraine Action Association

Tel: 0116 275 8317
Fax: 0116 254 2023
Email: info@migraine.org.uk
Web: www.migraine.org.uk

Migraine Action Association
4th Floor
27 East Street
Leicester
LE1 6NB

Established 1958
Registered Charity
No. 207783

Of those who had tried Botox, over 60% found the treatment beneficial or very beneficial.

The initial survey results have now led us to undertake a further “drilled down” survey with the following questions in an attempt to further discuss some of the issues raised in the preliminary recommendations. This survey can be found by visiting our website at www.migraine.org.uk

However we do have a number of observations to make which have been raised by some members over the last couple of weeks in response to the media activity.

Concentrating on the change in number of days of headache doesn't fully tell us how a patient has actually responds to treatment. It doesn't reflect “reality and relevance of transforming lives”.

For instance we have members real life experiences recorded who tell us that their “end point” was the improvement in their overall quality of life even though some days the headaches were still there. However the severity, length of headache and associated symptoms had improved to such an extent that these patients were not bedridden or unable to interact socially with their family and friends, or for some, do the school run for the first time in weeks and months.

Change in non headache symptoms may be key. We have patients whose dizziness was so much reduced that even on their “break through headache” days they were still able to travel on public transport and continue to work. This suggests that their QALY had been improved and this is not recorded in the studies.

We understand that any treatment needs to be cost effective. However what our members wish addressed is the need to demonstrate there was enough effect on the QALY to justify carrying on treatment.

Additionally, if successfully managed and then migraines were to return- how would they as patients be handled?

What would be the procedure to reenter the programme or would they be excluded until they had exhausted once again all other treatments and their migraines had worsened to a point where they reached the expected criteria. In our opinion this is discriminatory practice.

We trust that the enclosed may be of some help to the appraisal process.

Yours sincerely

A solid black rectangular redaction box covering the signature area.