

THE MACULAR DISEASE SOCIETY

CONSULTEE SUBMISSION FOR THE NICE REVIEW OF PEGAPTANIB AND RANIBIZUMAB

Introduction

1. The Macular Disease Society has worked closely with the RNIB to produce a joint submission to NICE for the review of pagaptanib and ranibizumab.
2. Uniquely the Society has very close daily contact with people with macular degeneration. We have therefore produced this short additional note to reflect the passionate concern of our members and the public about the introduction of the new treatments.
3. Reflecting the drug names in common use by clinicians, eye health professionals, the pharmaceutical companies and patients the names Macugen (pegaptanib) and Lucentis (ranibizumab) have been used throughout.

NICE Review Timescale

4. Macugen received its licence for use in UK in May. Lucentis is expected to receive its licence by December 2006 . The data and submissions for these therapies will be with NICE on 1st August. Why do patients have to wait for another year before NICE give a judgement on access to the new treatments on the NHS ? We submit that the timescale should be shortened and NICE fast track procedures should be implemented.
5. It is not reasonable to have new treatments which can prevent sight deterioration and bring about sight improvement sitting on the shelf unused for a year while NICE deliberates.
6. In theory clinicians can use any licensed treatment if they consider it suitable for their patient. However someone has to pay for it. In practice a few PCTs have authorised the use of Macugen as an alternative to PDT but the majority shelter behind the NICE process as a way of saving money particularly as a larger volume of patients is now suitable for the new anti-VEGF treatments compared with those suitable for PDT.
7. During the 12 month review period it is estimated that 26,000 new patients could be suitable for the new treatments. We are not happy for tried and tested new treatments to be denied to these patients condemning them to sight loss and to the impact on quality of life described fully in the joint RNIB/MDS paper.

Testing Decisions

8. We urge that throughout the review process the reviewing team think of patients as people rather than statistics. We suggest that they should apply a simple test to their logic and thought processes. This means each of the team considering whether they would be content for one of their

parents to be caught up in a restriction on the use of the new treatments which would lead to blindness in one or both eyes or would drive the family to seek treatment privately (the parental test). We ask that the parental test should be applied honestly to every judgement made in the final appraisal determination.

9. With many other conditions NICE can rule that other cheaper and more cost effective therapies should be used. In the case of CNV there are no cheaper alternatives at present therefore the only alternative to the new treatments is the inexorable development of blindness with all its acute distress, impact on quality of life and other costs. This makes the parental test more pertinent to central vision loss than to many other conditions.
10. If the parental test had been applied to the decision made about PDT that it could only be used for the second eye it is most unlikely that it would have reached publication. Unscrambling this first judgement took months and helped to contribute to the 2.5 years it took to reach a final decision.

Private Treatment

11. For as long as Macugen and Lucentis are not available on the NHS a small number of patients with sufficient means have the option of private treatment. We are fundamentally opposed to the concept of viable treatments for blindness being available only to those with the means to pay for them. This is grossly unfair and contrary to the principles of the NHS for which patients have contributed throughout their lives.

12. The costs of private treatment are shown here

Macugen (Pfizer)	Drug £500 Treatment regime Intravitreal injection every 6 weeks for up to 2 years Private cost £4,000 for one year
Lucentis (Genentech – distributed in UK by Novartis)	Drug: £1,200 Treatment regime Intravitreal injection every 4 weeks Good results show after 3 injections but regime must be maintained for a period not yet defined Private cost £2,000 per injection but can only be bought as a package of 3 for £6,000
Avastin (Genentech)	Drug: could be as low as £15 Treatment regime: undefined but probably similar to Lucentis Private: cost varies £500 - £800 per injection

13. To accept the principle that those who really want the treatments can seek private help would be wrong and certainly would not pass the parental test.

Conclusions

14. We request that the programme for evaluating Macugen and Lucentis should be speeded up to avoid delaying treatment to patients whose sight is deteriorating and could be saved.

15. The parental test should be applied to all decisions and judgements made by NICE to test them for common sense and avoid delay.

16. The possibility of acquiring private treatment should not be regarded as an acceptable alternative to receiving treatment free on the NHS.

17. The most important factor to take account of is whether the treatments are effective in stabilising vision or giving improvement. If they are, clinicians should be authorised and funded to give the treatments free at public expense.

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The Macular Disease Society

31st July 2006