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THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS

(In Association with Macmillan Cancer Support)

Mr C Feinman
Technology appraisal Project Manager
NICE
Level 1A City Tower
Piccadilly Plaza
Manchester
M1 4BD

President Mr IVOR SMITH
General Secretary
Ms VIVIEN REED

27 February 2008

Dear Mr Feinman,

NICE single technology appraisal Cetuximab for the treatment of Head & Neck
Cancer appraisal Consultation Document February 2008

NALC has been grateful for the opportunity to take a formal part in the decision processes undertaken, by NICE, on the use of "Cetuximab for the treatment of locally advanced squamous cell cancer of the Head and Neck" and hope that our inclusion will help NICE to understand the priorities of patients and carers.

As an organisation led and managed by patients and supported by carers we do have difficulties with some of the technical and medical evidence. Our remarks are based on our 'users' perception of the debate.

NALCs concern is that our stance is not seen as that of "patients wanting the latest drug". It is about how the development of better and less toxic treatments may be progressed as quickly as possible to reduce the need for more serious and traumatic interventions. It will furthermore give the patient a choice of treatment not available at present.

(Founder President, the late JOHN C. McCARTHY, C.B.E.)

PATRONS

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ACD Feb. 2008

i)

We consider that because of the rarity of these conditions the evidence needs to be viewed in a more flexible manner, especially in relation to the NHS economic argument, and the problems concerning the numbers of suitable patients for the research purposes.

We are concerned that the relatively small numbers in cohorts in each of the categories under consideration for the use of Cetuximab are to continue to restrict appropriate consideration of the merits of these treatments.

NALC is part of the Rare Cancers Forum and is aware of the concerns about these questions in Parliamentary circles and in the debates of prestigious research bodies such as the NCRI & UKCRC

In addition we feel that the facts illustrating that the mortality rate has not changed and no new drug has been identified in four or more decades should have been given some weighting. We further consider that the question of the toxicity of platinum based chemotherapy, particularly its use as an adjunctant to radiotherapy, has also not been given sufficient thought.

ii)

We consider that the evidence of the rarity of head and neck cancers have not been given any weighting in the appraisal from the beginning of this whole process especially in relation to the economic, cost effectiveness question. Other financial considerations also have not been addressed such as, that given the rarity, numbers to be treated will be relatively low, as will the consequential costs to the health sector.

It would also appear that when considering NHS costs the review failed to take into account the long term and ongoing costs to Primary and Social Care of supporting patients who undergo conservative surgery for these conditions.

iii)

While we welcome the suggestions on research: (ACD: Page 16: 6.2) NALC has members working as consumers in the research field and we are aware that proposals for research using Cetuximab answering just the questions you require are being hampered by the lack of NICE recognition of the drug. We suggest that the (last 3 paras: page 7: The Evaluation Report) are considered very seriously even if it is just that you provide a "within research" recommendation. This should speed up research proposals considerably.

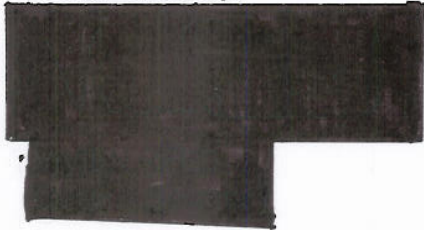
A number of our comments and opinions in this review were put forward at the initial hearing and when the expert patients were required to leave the hearing our representative understood that these views were to be fully taken into account. However, when attempting to understand the final appraisal finds we



found it difficult to trace and particular mention of those discussions either in the first appraisal or the following appeal attended by both our representatives as observers.

For this reason we hope that our comments do not seem at odds with the documentation or out of kilter with the rest of the evidence. Again, thank you for our inclusion in this process.

Yours sincerely,

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