MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk

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31/7/13

Re:Response to ACD:Myelodysplastic syndrome (deletion 5q) - lenalidomide [ID480]

Dear Committee members,

We respond on behalf of the MDS UK Patient Support Group to to this ACD. The particular points below refer to the relevant paragraph numbers.

4.9 Though lenalidomide confers no advantage over BSC in respect of time of progression to AML, the important issue for patients is the improvement in their quality of life. It is our universal experience that transfusion dependent patients are far more concerned about the quality of the life that they have rather than its overall duration. The fact that the time for progression to AML is not altered by lenalidomide is not an issue for patients who have to travel to hospital several times a month to receive frequent transfusions, but still suffer from poor energy, due to low haemoglobin levels. These patients are unable to have a normal day to day life – as opposed to patients on lenalidomide, whose haemoglobin levels have stabilised.

4.13 The ICER calculations are widely varied. The reason for this appears to be the range of scenarios considered in terms of transfusion dependence/independence. Some of the calculations are extrapolated from data involving a small number of patients. In the discussion at the appraisal the committee appeared to be disagreeing with the results of the ERG analysis. This disagreement appears to be reflected in the ACD which makes the spread of ICERs too broad to allow a sensible decision to be made.

The level of the ICER may become critical should a Patient Access Scheme be introduced. We ask that the committee considers this in setting and agreeing an ICER as the present divergent values may render lenalidomide too costly to be available to those patients who can benefit from it.

4.14 The emphasis here is entirely on overall length of survival with no consideration for quality of life during treatment, which is of paramount importance to patients. The issue is quality of life over a much shorter period of a few years rather than the twenty years used in the model.

Kindest regards,

Rodney Taylor
Chairman – MDS UK Patient Support Group
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