1 June 2009

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Dear Bijal

Re: ACD for ustekinumab for the treatment of adults with moderate to severe psoriasis

Thank you for the opportunity to comment on the above ACD.

We welcome the preliminary recommendation of ustekinumab as a treatment option for moderate to severe psoriasis.

As an organisation which is primarily patient driven, our concerns for the use of these treatments are still around the long-term adverse events. We believe that the treatment needs to be carefully prescribed by an appropriate centre and trained specialist.

In section 6 of the ACD Research recommendations, we believe that stronger emphasis should be placed on head-to-head trials with other biologic agents, in order to see which perform more effectively, provide best use of available funds whilst avoiding serious adverse events.

We also think that the sentiments in NICE guidance TA 103 etanercept and efalizumab for treatment for adult with psoriasis Section 6 item 6.2 as set out below should also be included in all guidance related to use of biologics in psoriasis:

The Charity for people with psoriasis and psoriatic arthritis

PAPAA the new single identity of the
Psoriasis Support Trust and the Psoriatic Arthropathy Alliance
and is a Company Limited by Guarantee, registered in England and Wales No: 6074887
Registered office: Registered Office: Acre House 11-15 William Road London NW1 3ER
"6. Recommendations for further research.

6.2 Efforts should be made to ensure the rapid establishment of the proposed BADBIR. This will enable the collection of information on long-term outcomes including adverse events, and also potentially facilitate the identification of subgroups of people who respond better to the drugs. Procedures should be implemented to allow cross-referencing of BADBIR with information from people with PsA enrolled in the British Society for Rheumatology biologicals register" TA103.

The BADBIR is now established and recruiting and therefore an implicit statement in NICE guidance will make those prescribing more likely to enter patients into the register or refer to centres which are more equipped to carry out this important process in patient safety.

With more of these agents in research, it would be an advantage to patients if the manufacturers took on board that considering the number of established therapies currently available with NICE guidance, future research with biologic agent comparators should been seen as a priority of research and evidence submissions.

With best wishes

David Chandler
Chief Executive