Dear [redacted],
I would like to comment on clinical aspects of the Appraisal document.
On a general note I am surprised and disappointed that the committee are minded not to approve Tocilizumab for Systemic Onset JIA. The negative approval status from NICE will make it very much more difficult for the small number of severely affected patients with this condition to gain access to what is undoubtedly an effective treatment.
I believe setting the treatment age at 5 years for treatment is not clinically justified. The appraisal document recognises that disease onset is as early as 2 years and that children under the age of 5 years are the worst affected. If a child of 2 years develops the condition and then goes on to fail steroids and Methotrexate over the course of the next 12 months the child will then have to wait up to 2 years before they are eligible for the most appropriate treatment. A starting age of 2 or 3 years makes the best clinical sense.
The stopping rule for Tocilizumab at 2 years is too rigid, some patients will need treatment for longer and the recommendation that treatment interval is increased to 4 weeks at 6 months may also not be achievable by all patients. These decisions should not be taken by a committee such as NICE but left to the expert treating clinician.

I believe that although there is some controversy with regard to how the data in the TENDER trial was analysed the results are unequivocal and the beneficial effect of Tocilizumab is very clear and far superior to any other known treatment. The number of patients with systemic onset JIA in the UK is relatively small but the effect on individuals and their families is often devastating. The burden of care on the treating units is also high when these patients are constantly unwell. These factors should be given more weight when coiming to a conclusion about the cost effectiveness of the treatment.
Thank you for passing on my comments to the appraisal committee.
Yours sincerely
Dr Jeremy Camilleri
Consultant Rheumatologist.