Response to Public Comments From the Authors for the ACR Update of the JIA Guideline Development Project

We greatly appreciate the thoughtful comments from members of the pediatric rheumatology community regarding the proposed update of the 2011 ACR juvenile idiopathic arthritis treatment recommendations. Overall, the public comments received could be categorized into three primary areas: 1) personnel, 2) methodology, and 3) additional topics for consideration.

Several respondents commented on the composition of the Core Expert and Task Force Panels. Specifically, suggestions were made to include international experts, experts in the field of macrophage activation syndrome, and experts in some of the newer biologic medications being addressed in the recommendations. In response to these suggestions, 2 additional international experts in JIA (Drs. Martini and Dolezalova) were added to the Task Force Panel. As macrophage activation syndrome was not a major focus of the effort, we did not elect to include an expert in this field. The Core Expert Panel, as initially formed, did include experts who have led trials evaluating the interleukin1 antagonists.

Alternate methodology, other than the RAND/UCLA method, was suggested. However, the ACR commissioned the update and specified use of the RAND/ULCA method because this project was a partial update of the 2011 JIA guideline, for which the RAND/UCLA method was used. Other than similar partial updates of previous ACR guidelines that used RAND methodology, the ACR intends to use the GRADE approach for future guideline development projects. It was also suggested that we incorporate publications in languages other than English into the Evidence Report. We were unable to include these articles due to lack of resources for translation. It was also recommended that grading systems, including QUORUM and STROBE, be applied to the articles included in the Evidence Report. Different approaches to the grading of evidence were discussed with members of the CEP and the consensus were observational in design and although formal rating system(s) could be applied, the majority were small case series for which the rating systems were not necessarily designed and unlikely to be informative. Furthermore, it was felt that these ratings would not significantly impact voting. The Jadad rating was used for evaluation of randomized controlled trials and included in the Evidence Report.

Several other minor methodology issues were addressed, including placement of sulfasalazine in the category of disease modifying anti-rheumatic agents. There was also a suggestion to incorporate information form established JIA registries and not to rely solely on published literature. While this is an intriguing suggestion, we were unable to incorporate unpublished details from the registries under the RAND/UCLA methodology. We sincerely hope these registries will be utilized to study and publish information on the effectiveness and safety of the medications under consideration so that information will be available for future update efforts.

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Many respondents listed additional topics to consider as part of the scope of the update, including the following: role of vaccination in children on biologics, length of therapy after attainment of inactive disease, risk of macrophage activation syndrome from interleukin-1 or -6 inhibitors, use of folic acid with methotrexate, route of methotrexate administration, liver biopsy indications while on methotrexate, radiologic guidance for joint injections, treatment of uveitis, TMJ arthritis, and hydroxychloroquine toxicity screening. While we agree that all of these issues are of clinical importance, we regret they were not feasible to incorporate into the scope of the project. We encourage those who suggested these topics to actively participate in the design and scope of future efforts, particularly if they have specific knowledge and expertise that is sought.