Authors' Response to Public Comments on the Project Plan for the 2021 ACR Juvenile Idiopathic Arthritis Guideline

October 2019

We greatly appreciate the thoughtful comments from members of the pediatric rheumatology community regarding the proposed ACR juvenile idiopathic arthritis treatment recommendations. The questions and our responses are summarized as follows:

1. "Curious as to why herbal supplements are being explored."

Herbal supplements are considered in these guidelines as studies have shown that somewhere between 34-92% of children with JIA use some type of complementary and alternative treatment. (Nousiainen P, et al. BMC Complement Altern Med. 2014:14;124).

 "Rather than exploring preferred order of treatment, the panel should strongly consider an inverted pyramid approach to therapy, starting aggressively and backing off of therapy when prolonged remission is achieved. A 'window of opportunity' likely exists for all forms of JIA."

The literature review team will review all appropriate articles that include treatment options as stated. After review, the voting panel may comment on timing should sufficient evidence exist. Given diseases discussed in this report, combination therapy is less likely to be used. Discussion of medication withdrawal is beyond the scope of these guidelines.

3. "Should line 461, page 21, be changed to include screening for 'common regional fungus infections' (for example, histoplasmosis in Midwest/mid-south)?"

We have elected to keep the category broad as patients may travel or move from one region to another and therefore location is not specified.

4. "The proposed project plan entails several systematic reviews (oligo, TMJ, vaccinations, other) and follows a traditional recipe. It is important to include more content experts for several of these areas in order to define the scope appropriately. I would suggest including experts of biomarkers beyond Peter Nigrovic for oligo, since the risk factor part was weak in the last versions. I would also suggest adding TMJaw board members for the TMJ treatment, since it is outside of the scope of most rheumatologists (which includes the PICO table and search terms). Overall, given the scope, having a larger, more inclusive team would probably increase the acceptance of what is produced. The SHARE approach is a great example for early broad inclusiveness. Also, adding patient and families has been one of the secrets to relevance. I would consider."

We agree that adding a member of the TMJ Juvenile Arthritis Working Group who has published extensively in this area as well as an expert in the basic underpinnings of JIA would help to strengthen the validity of the recommendations. We appreciate the suggestion.

The voting panel includes two patient members. There is an additional parent/patient advisory board whose recommendations are reviewed by the voting panel and included in the quidelines as appropriate.

5. "I recommend that you include a subsection that addresses transition and transition readiness into adult care. Even if it's a small section, including it will emphasize to pediatric rheumatologists and healthcare systems that this is important enough to be recommended by national subspecialty guidelines. I'm sure patients and parents will agree."

We agree that transition of patients between pediatric and adult rheumatology remains a critical area for study and in need of guidelines. Specific recommendations remain beyond the scope of this set of guidelines as they largely address the onset of treatment and the safe usage of these treatments.

6. "I applaud the ACR for attempting to address issues unaddressed in the preceding iteration of the JIA treatment guidelines. I am also glad to see that the goals of this project specifically address 'pharmacologic and non-pharmacologic' treatments. I reviewed the PICO list and see several PICOs focusing on PT, OT or 'non-medical' treatments. I was therefore quite surprised to see no members of the core oversite team, literature review team or voting panel with PT or OT credentials. That may also explain why the 6 aims of the project include pharmacologic treatments or imaging questions with no mention of 'non-medical' treatments. If the goal of this project is to include a review of non-pharmacologic interventions, then I urge the core team to add PT/OT representation to the core team and to the voting panel at least."

We agree that adding a PT/OT representative would help to strengthen the validity of the recommendations. We appreciate the suggestion and have added a PT as a consultant to the guideline project.