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IDENTIFYING RESEARCH PRIORITIES FOR JUVENILE I対PATHE T ARTHITIS TOGETHER WITH PATIENTS, CAREERS AND CLINICIANS THROUGH THE JAMES LINDE ALLIANCE METHOD: PRELIMINARY RESULTS

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Background: Research on Juvenile Idiopathic Arthritis (JIA) should have the primary goal to ultimately improve the lives of the affected patients and help health professionals provide the best care for them. Therefore, these end users of research evidence – patients, carers (parents/caregivers) and clinicians – should be included in the process of identifying research priorities. Importantly, patients and carers can use their unique experiential knowledge from living with the disease to give vital input to researchers in designing a study. Combining this input with the goal of research(ers) to make a true impact on patients’ lives, will result in research that is more effective and meaningful, and thereby increases research relevance.

Methods: To this end, we initiated the project of establishing a research agenda for JIA jointly by patients, carers and clinicians.

Objectives: The objective of this project is to bring patients, carers and clinicians together to identify research priorities and create a research agenda for JIA, such that future research into JIA is guided to the issues that matter most.

Results: A total of 321 PFAPA, 118 FMF and 45 JIA patients with mean age of 7.2±2.9, 14.7±3.09, 13.5±2.6 years, respectively, were included in the study. A 45% (146/321) of PFAPA, 50% (59/118) of FMF and 58% (23/45) of JIA patients were female. We found quite high sensitivity (90%) of newly proposed PFAPA criteria: 289 out of 321 (90%) patients followed up as PFAPA syndrome fulfilled newly proposed PFAPA criteria, as well. When applied to patients diagnosed with FMF and JIA, 46 out of 118 (39%) FMF and 10 out of 45 (22%) JIA patients also fulfilled newly proposed PFAPA criteria. Positive predictive value was 86% and 97%, negative predictive value was 69% and 50% for FMF and JIA patients, respectively. Successful predictive value was 86% and 97%, negative predictive value was 69% and 50% for FMF and JIA patients, respectively. Positive predictive value was 86% and 97%, negative predictive value was 69% and 50% for FMF and JIA patients, respectively. Positive predictive value was 86% and 97%, negative predictive value was 69% and 50% for FMF and JIA patients, respectively.

Conclusion: Recently proposed PFAPA criteria have satisfactory high sensitivity. Specificity of recently proposed PFAPA criteria was found to be 61% and 77%, among FMF and JIA patients, respectively. Positive predictive value was 86% and 97%, negative predictive value was 69% and 50% for FMF and JIA patients, respectively.

REFERENCES: