



## **THE MAIN CHALLENGES FOR CHILDHOOD-ONSET SYSTEMIC LUPUS ERYTHEMATOSUS TREATMENT: A SURVEY IN LATIN AMERICA**

Juliana Caires Ferreira (Instituto da Criança e do Adolescente HC-FMUSP, São Paulo, SP, Brasil), Vivianne Saraiva Viana (Instituto da Criança e do Adolescente HC-FMUSP, São Paulo, SP, Brasil), Vitor Cavalcanti Trindade (Instituto da Criança e do Adolescente HC-FMUSP, São Paulo, SP, Brasil), Tamima Mohamad Arabi (Instituto da Criança e do Adolescente HC-FMUSP, São Paulo, SP, Brasil), Juliana Russo Simon (Instituto da Criança e do Adolescente HC-FMUSP, São Paulo, SP, Brasil), Graciela Espada (Hospital de Niños Dr Ricardo Gutierrez, Argentina), Zoilo Morel (Hospital de Clinicas, Universidad Nacional de Asunción, Paraguai), Cláudia Saad Magalhães (Faculdade de Medicina de Botucatu da Universidade Estadual de São Paulo (UNESP), São Paulo, SP, Brasil), Eloisa Bonfá (Universidade de São Paulo, São Paulo, SP, Brasil), Clóvis Artur Silva (Universidade de São Paulo, São Paulo, SP, Brasil)

### **BACKGROUND**

We recently reported a survey with Latin America Pediatric Rheumatologists (LAPR) regarding epidemiology and management practices for childhood-onset systemic lupus erythematosus (cSLE) patients, including multiple choice-response or dichotomous questions. This first large web-based survey demonstrated an overall access for diagnosis and therapy by LAPR. However, one relevant open-ended question regarding challenges for cSLE treatment reported by LAPR was not previously described. Therefore, the objective to our study was to evaluate the main challenges reported by LAPR during their practice with cSLE patients, and its relation with years of LAPR practice.

### **MATERIALS AND METHODS**

A cross-sectional study was done with 288 LAPR Pan-American League of Association for Rheumatology (PANLAR) members based on online survey about cSLE practices. The response rate of web-based survey by LAPR was 170/288 (59%). The questionnaire included an open-ended question: "What are the most important challenges for cSLE treatment in your service and your country in general?".

### **RESULTS**

Incomplete data were observed in 14/170 (8%), and therefore 156/170 (92%) responses were evaluated of 16/21 (76%) LA countries. The main challenge for cSLE treatment reported by LAPR was non-adherence to therapy  $n=64$  (41%). Further analyses compared LAPR into two groups according the median years of practice: Group A ( $\leq 12$  years of LAPR practice,  $n=82$ ) and B ( $> 12$  years,  $n=74$ ). The frequencies of Groups A and B were similar regarding: non-adherence to therapy (39% vs. 43%,  $p=0.672$ ), biological agents availability (31% vs. 30%,  $p=0.863$ ), non-biological agents availability (29% vs. 36%,  $p=0.394$ ), imaging studies availability (4% vs. 3%,  $p=1.000$ ), other exams availability (16% vs. 12%,  $p=0.641$ ), transition plan to appropriate adult health care provider (11% vs. 18%,  $p=0.258$ ), limited access for multiprofessional approach (12% vs. 13%,  $p=0.816$ ), limited access for specialized physical approach (22% vs. 20%,  $p=0.846$ ), socio-economic issues (22% vs. 26%,  $p=0.706$ ), and public health policies and services issues (37% vs. 38%,  $p=1.000$ ).

### **CONCLUSION**

This first large web-based survey demonstrated a diversity of challenges for cSLE treatment reported by LAPR. Non-adherence to therapy, public health policies and services issues and non-biological agents availability were identified as major challenges in this population. In addition, these challenges were not influenced by time of professional practice.