Conclusions WWE is a feasible, low-cost program that may decrease SLE-related fatigue and stiffness, improve activity and promote long-term lifestyle changes.

**Trial registration** ClinicalTrials.gov Identifier: NCT02631005.

**Background** Compared to adult-onset SLE, childhood onset SLE (cSLE) tends to present with more severe disease and more widespread organ involvement. Additionally, cSLE associated with higher mortality and damage accrual. However, despite the severity of the disease few commonly used SLE medications have been rigorously studied in children, and important knowledge gaps remain concerning the epidemiology, natural history, pathophysiology, genetics and optimal treatment of cSLE. In order to identify high priority areas for future research in cSLE, the Lupus Foundation of America (LFA) and the Childhood Arthritis and Rheumatology Research Alliance (CARRA) partnered to perform and cSLE research prioritization survey.

**Methods** Using information from the 2013 CARRA Lupus Group Research Prioritization Exercise and the most recent LFA Parent and Caregiver Survey, we identified areas of clinical and research need in cSLE. A work group was assembled to develop and refine survey questions which ask clinicians and researchers to rank research topics that are most urgent advance patient outcomes. The survey was programmed using Qualtrics software. The survey was beta tested by a separate group of clinicians and researchers. The proposed survey administration was deemed not to be human subjects research by the University of Utah and Nationwide Children’s Institutional Review Boards. Descriptive statistics will be used to analyze survey responses.

**Results** The survey will be administered to members of CARRA and also to collaborators in the inflammatory skin disease interest group of the Pediatric Dermatology Research Association (PeDRA) and the glomerulonephritis interest group of the Midwestern Pediatric Nephrology Consortium (MWPNC). Together, these organizations include over 800 clinicians and researchers.

**Conclusions** The results of the CARRA/LFA Research Prioritization Survey will be used to guide funding programs for cSLE within the Lupus Foundation of America, to share with potential donors, and to use in advocacy efforts promoting state and federal funding for cSLE.