



POSTER PRESENTATION

Open Access

SHARE – workpackage 5 : evidence based recommendations for diagnosis and treatment of childhood-onset systemic lupus erythematosus

Noortje Groot^{1,2,3*}, Nienke de Graeff³, Tadej Avcin⁴, Brigitte Bader-Meunier⁵, Paul Brogan⁶, Pavla Dolezalova⁷, Brian Feldman⁸, Isabelle Kone-Paut⁹, Pekka Lahdenne¹⁰, Alberto Martini¹¹, Liza McCann¹, Seza Ozen¹², Clarissa Pilkington⁶, Angelo Ravelli¹¹, Annet van Royen³, Bas Vastert³, Nico Wulffraat³, Sylvia Kamphuis², Michael Beresford¹

From 21st European Pediatric Rheumatology (PReS) Congress
Belgrade, Serbia. 17-21 September 2014

Introduction

Childhood-onset systemic lupus erythematosus (cSLE) is a rare multisystem autoimmune disease that often leads to significant morbidity. Evidence-based guidelines are sparse and management is mostly based on physician's experience. Consequently, treatment regimens differ throughout Europe. In 2012, a European initiative called SHARE (Single Hub and Access point for paediatric Rheumatology in Europe) was launched to optimize and disseminate diagnostic and management regimens in Europe for children and young adults with rheumatic diseases such as cSLE.

Objectives

To develop evidence-based recommendations for diagnosis and treatment of cSLE.

Methods

Evidence based recommendations were developed using the European League Against Rheumatism (EULAR) standard operating procedure. An expert committee, consisting of paediatric rheumatologists from across Europe with expertise in cSLE, defined search terms for the systematic literature review. Two independent experts scored articles for validity and level of evidence. Through an online survey, experts evaluated recommendations derived from the literature. The recommendations were discussed at a consensus meeting using the

nominal group technique¹. Recommendations were accepted if more than 80% agreement was reached.

Results

The literature search yielded 9341 articles, of which 128 (75 for diagnosis; 53 for treatment) were considered relevant and therefore scored for validity and level of evidence. Only sixteen articles (4 for diagnosis; 12 for treatment) were deemed valid; a larger number of articles were scored moderately valid (62 for diagnosis, 25 for treatment). Both were used in the formulation of the recommendations. Eighteen recommendations for diagnosis and 24 for treatment were suggested in the online survey. Thirteen recommendations for diagnosis and 14 for treatment were accepted with more than 80% agreement during the consensus meeting. Table 1 summarizes the categories of recommendations.

Conclusion

The SHARE initiative provides recommendations for diagnosis and treatment for cSLE and thereby facilitates improvement and uniformity of care throughout Europe. Currently, a similar process is going on to add further guidelines including those on treatment and holistic care for PRD patients. As a final result, SHARE will provide standards of minimal care for different PRDs, including cSLE.

Disclosure of interest

None declared.

¹Alder Hey Children's Hospital, Liverpool, UK
Full list of author information is available at the end of the article

Table 1

Recommendations regarding:	Number
Diagnosis:	
Classification	3
Laboratory features	2
Access to other specialities	2
Comorbidities (growth/MAS/ hereditary conditions)	3
NP-SLE	
Acknowledgement of necessary research	2
	1
Treatment	
General	2
Haematological involvement	1
Lupus Nephritis (Class III/IV/V)	8
Compliance	1
NP-SLE	2

Authors' details

¹Alder Hey Children's Hospital, Liverpool, UK. ²Erasmus MC-Sophia, Rotterdam, Netherlands. ³University Medical Centre Utrecht, Utrecht, Netherlands. ⁴University Medical Centre, Ljubljana, Slovenia. ⁵Necker Hospital, Paris, France. ⁶Great Ormond Street Hospital, London, UK. ⁷General University Hospital, Prague, Czech Republic. ⁸Sick Kids Hospital, Toronto, Canada. ⁹CHU de Bigetres, Paris, France. ¹⁰Children's Hospital of Helsinki and Uusimaa, Helsinki, Finland. ¹¹Gaslini Children's Hospital, Genova, Italy. ¹²Hacettepe University Children's Hospital, Ankara, Turkey.

Published: 17 September 2014

doi:10.1186/1546-0096-12-S1-P109

Cite this article as: Groot *et al.*: SHARE – workpackage 5 : evidence based recommendations for diagnosis and treatment of childhood-onset systemic lupus erythematosus. *Pediatric Rheumatology* 2014 12(Suppl 1):P109.

Submit your next manuscript to BioMed Central and take full advantage of:

- Convenient online submission
- Thorough peer review
- No space constraints or color figure charges
- Immediate publication on acceptance
- Inclusion in PubMed, CAS, Scopus and Google Scholar
- Research which is freely available for redistribution

Submit your manuscript at
www.biomedcentral.com/submit

