



SLE Working Group

ANNUAL REPORT 2017:

2016 Meeting – Genoa

Over 30 members met at our yearly PRES cSLE Working Party meeting. The overlap of other PRES working party meetings at the same time unfortunately limited attendance, but we had a very fruitful meeting.

The minutes and the copies of the powerpoint presentations were circulated to all to have a complete update of what was discussed and agreed upon.

It was a fruitful meeting with a lot of positive discussion and participation. Along with the PRES-endorsed SHARE SLE/APS recommendations, a number of other studies were discussed involving SLE Working Party members. Updates on all of these, and new proposals emerging, will take place at the 2017 meeting in Athens, 14th September 2017.

1. SHARE: Lupus and APS Recommendations

This PRES-endorsed European initiative was completed in 2015, developing evidence based minimal standards of care for diagnosis and treatment of pediatric autoimmune diseases including cSLE and APS. Many of the Working Group have been involved in this, which was a very demanding project.

This year, three manuscripts are being finalized and published /accepted for publication in Annals of Rheumatic Disease. This has been a significant piece of work for many members of the Working Party, and a great step forward.

Along with the rest of the SHARE initiative, a key question for all is: What happens next? Initial consideration of how the recommendations can or should be implemented took place also at the EULAR meeting in Madrid, and the SLE Working Party looks forward to contributing to this wider discussion, whilst also considering specific aspects of the SLE and APS recommendations

2. PEDOLUP Study – Multicenter (France, Switzerland, Belgium) pediatric-onset SLE cohort

This study which is being led by Brigitte Bader-Meunier and Alexandre Belot in France was presented, and all expressed great interest and support for this important initiative. Members were invited to contact Brigitte and Alex directly for more information.

3. Developing a minimal clinical cSLE dataset.

This was proposed arising from SHARE and other collaborative studies, with the aim to use this dataset to facilitate international research projects and potentially setting up an international data set supported by the PRES cSLE WP. Volunteers to develop a small working group of any senior individual representative from centres / countries with established cohorts and clinical data collection, have been sought, with the support of a local trainee who could help with the project. Update and next steps to be discussed in Genoa meeting.

4. Adult outcomes of cSLE

Noortje Groot presented an update from her important study of adults who had childhood onset SLE. An important discussion took place following this, highlighting many aspects emerging from these data, also in relation to long term damage. Noortje was congratulated on excellent work, which she is continuing and submitting for publication and her PhD.

5. Flare and Damage Assessment

Hermine Brunner updated the group on the on-going work related to Flare Criteria, that many members have contributed to. In addition, some important considerations with regard assessment of Damage in cSLE. Members have been invited to participate in online questionnaires to support this work, and representatives will attend a consensus meeting that took place in Cincinnati in 2017.

6. Use of corticosteroids in cSLE.

Sylvia Kamphuis updated the group on considerations regarding this crucial and complex part of cSLE management. The group gave full support to the proposal to facilitate optimal use of prednisone in cSLE and develop more uniform prednisone treatment schedules between the different centers.

7. APS Update

Tadej Avcin gave an important update on the significant work of the European and International paediatric APS community, and the range of important studies that are on-going. Update and next steps to be discussed in Athens meeting.

A full update on all of these, plus new proposals will be discussed at the meeting in Athens.

Michael Beresford (Chair), Tadej Avčin (Deputy Chair), and Sylvia Kamphuis (Secretary), on behalf of the PRES SLE Working Group