
Minutes

EASI Forum

Porto, February 6, 2013

Participants: Yehuda Shoenfeld (IL), Nancy Agmon-Levin (IL), Jan-Willem Cohen-Tervaert (NL), Jan Damoiseaux (NL), Carlos Dias (PT), João Faro Viana (PT), Manfred Herold (AT), João Pedro Ramos (PT), Aresio Plaza López (ES), Maria José Rego de Sousa (PT), Cees Kallenberg (NL), Lucile Musset (FR), Olli Vianio (FI)

Thermo Fisher Scientific: Eckart Mummert (DE), Nina Olschowka (DE)
Carmen Andalucia (ES), Teresa Araujo (PT), Sune Sved (FI), Gerben Zuiderveld (NL),

Protocol: Nina Olschowka

Agenda

1. Status of the recommendations on ANA testing (Nancy)
2. Status of the paper on the questionnaire on ANA testing (Jan)
3. How will we go forward with the ANA questionnaire for clinicians? (all)
4. ANCA questionnaire – next steps (Jan)
5. EASI questionnaire on APS (Yehuda)
6. EASI book "The General Practice Guide to Autoimmune Diseases" – local activities to distribute it and feedback (all)
7. New EASI booklet: content, authors, time line (all)
8. Projects of local EASI groups – inspiration for other groups? (all)
9. Next EASI forum meeting

1. Status of the recommendations on ANA testing (Nancy)

A manuscript of the paper was sent to all EASI groups. Nancy Agmon-Levin showed a presentation with the main points to be discussed (attached to this protocol):

1.1 Heading

in the manuscript there are two alternatives for headings. It was discussed whether it is the right time to introduce a new terminology for ANA/ENA. Nancy Agmon-Levin underlined that it is a unique possibility to introduce nomenclature changes with this article as more than 40 Autoimmunity specialists are involved. It was agreed that a new terminology will be introduced later, but its introduction will be prepared by choosing the first title alternative: "International recommendations for the assessment of autoantibodies to cellular antigens referred to as anti-nuclear antibodies (ANA)"

1.2 Table 3

Table 3 is a list of IIFA patterns and the associated antigens and diseases. It was discussed, that this table should be kept but the legend should i) differentiate patterns which should be reported by all labs from those which should be reported by expert labs, in addition. ii) The legend should state clearly that most patterns may be caused by antibodies against antigens which are not known.

1.3 Authors

all EASI groups are asked to send as soon as possible the name of the person who should be mentioned as author for the respective EASI group. Please send additionally the names of all other EASI members to

Nancy (nancy.agmon-levin@sheba.health.gov.il), so that they can be mentioned in the list of contributors, probably at the end of the article.

1.4 Where to be published?

All participants agreed that the paper should be submitted to Ann Rheum Dis. Only if the publication in Ann Rheum Dis is rejected or very difficult and delayed, the publication in Autoim Rev would be regarded as an alternative.

1.5 Suggestion for reviewers

All EASI members are asked to send proposals for reviewers of the article (not being authors) to Nancy by e-mail (nancy.agmon-levin@sheba.health.gov.il). A list of five to ten suggested reviewers would be good to have.

2. *Status of the paper on the questionnaire on ANA testing (Jan)*

Jan Damoiseaux presents the major findings of the ANA questionnaire. A manuscript does not exist yet but Jan will write it as soon as possible.

3. *How will we go forward with the ANA questionnaire for clinicians? (all)*

Due to the lack of time, this point was not discussed but shall be discussed in Dresden.

4. *ANCA questionnaire – next steps (Jan)*

Several labs in the Netherlands and some special labs worldwide were asked to fill in an ANCA questionnaire. The questionnaire is attached to this protocol. The EASI forum group wants to proceed in the same way as with the ANA questionnaire: all EASI groups are asked to send the questionnaire to labs and collect the data. All locally collected data should be sent to jan.damoiseaux@mumc.nl. Translations of the questions are possible but please do not change the questions, even when they seem to be not optimal for the local conditions.

5. *EASI questionnaire on APS (Yehuda)*

A questionnaire on measurement of antiphospholipid antibodies was developed. It is attached to this protocol. The EASI forum agrees that the ANCA- and the APS-questionnaire should be sent out together. Please handle translations and adaptations in the same way as the ANCA questionnaire. Results should be collected and sent to nancy.agmon-levin@sheba.health.gov.il.

6. *EASI book "The General Practice Guide to Autoimmune Diseases" – local activities to distribute it and feedback (all)*

Due to the lack of time, this point was not discussed. Copies of the book are stored at Phadia GmbH in Freiburg, Germany, and can be ordered by e-mail to nina.olschowka@thermofisher.com.

7. *New EASI booklet: content, authors, time line (all)*

Due to the lack of time, this point was not discussed but shall be discussed in Dresden.

8. *Projects of local EASI groups – inspiration for other groups? (all)*

Due to the lack of time, this point was not discussed but shall be discussed in Dresden.

9. *Next EASI Forum Meeting*

The next two EASI Forum meetings will be held attached to the Dresden Congress on Autoantibodies in autumn 2013 and on the 9th International Congress on Autoimmunity in Nice, May 2014. All attendees agree that next meetings should be planned for 2 hours minimum. Lunch meetings of an hour, even when twice a year, are not sufficient to discuss appropriately all activities. Eckart Mummert will ask Karsten Conrad to extend the lunch break to 2 hours on the day of the Dresden Congress when the EASI forum

meeting will take place.

Attachments:

- Presentation of Nancy Agmon-Levin "EASI Porto 2013 Standardization of ANA"
- Presentation of Jan Damoiseaux "EASI Porto 2013 ANA questionnaire results"
- ANCA questionnaire to be sent out by local EASI groups "EASI questionnaire on ANCA"
- APS questionnaire to be sent out by local EASI groups "EASI questionnaire on APS"