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## **Minutes**

### **EASI Forum**

Dresden, September 2, 2013; 12:30 – 14:30 h

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**Participants:** Yehuda Shoenfeld (IL), Xavier Bossuyt (BE), Jan Damoiseaux (NL), Catharina Eriksson (SE), Boris Gilburd (IL), Andrea Griesmacher (AT), Arno Hänninen (FI), Manfred Herold (AT), Olof Hultgren (SE), Aresio Plaza López (ES), Lucile Musset (FR), Antonella Radice (IT), Stephan Regenass (CH), Johan Rönnelid (SE), Bernhard Schlüter (DE), Günter Steiner (AT), Markku Viander (FI)

**Thermo Fisher Scientific:** Eckart Mummert (DE), Nina Olschowka (DE), Juan Jimenez (ES), Jari Siuro (FI), Lilian Larsson (SE), Emilie Le Floch (FR), Anne Omholt (NO), Udo Schlosser (DE), Gerben Zuiderveld (NL)

**Protocol:** Nina Olschowka

#### **Agenda**

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

#### **1. Status of the publication on recommendations on ANA testing (Yehuda)**

Great thanks to Jan Damoiseaux and particularly to Nancy Agmon-Levin who both were very engaged. The paper is re-submitted at the Ann.Rheum.Dis. As soon as the paper is published, Nina will inform the EASI members.

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

The paper is ready to submit to Autoim.Rev. There was not a response from all countries but it will be finalized with the input Jan got so far.

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

The questionnaire was carried out in Portugal and Finland. France has started. These three EASI groups are asked to send their questionnaires (in English – did they all use the same template from Portugal?), their experience and some comments what should be improved or what should be considered for using the questionnaire in other countries. Manfred Herold and Jan Damoiseaux volunteered to check the questionnaire and send it to some selected clinicians. According to their feedback and the tips from France/Finland/Portugal they will adapt the questionnaire and make a proposal to use it for the other EASI groups.

Which clinicians should be involved? General Practitioners, Internists, Rheumatologists...? Depending on country, who are the typical senders asking for ANA. Has to be stated in the questionnaire.

The aim of the questionnaire is a publication such as “Do physicians talk to lab people and vice versa?”

The French EASI group discussed the implementation of **RF and CCP** in the questionnaire. The group decided to address this but in two separate questionnaires (for labs and clinicians, respectively). Manfred Herold and Lucile Musset will prepare a proposal.

#### **4. ANCA questionnaire (Jan)**

In the Netherlands an ANCA questionnaire for labs has been done. The results will be published in a Dutch journal. The questionnaire is attached to this protocol. In contrast to ANA the article contains no recommendations as Dutch guidelines exist already.

The EASI forum group decided in Porto 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. Nina will send around the questionnaire once more in a separate mail and will put it on the EASI website. All locally collected data should be sent to [jan.damoiseaux@mumc.nl](mailto:jan.damoiseaux@mumc.nl). Finland, Spain and Portugal have answered already with final results.

For ANCA it is also planned to go on with a questionnaire for clinicians. Jan will ask Jan-Willem Cohen-Tervaert (who is a clinician) to help him with formulating the questionnaire. If this doesn't work, Yehuda and Nancy Agmon-Levin will take care of it.

Additionally, a multicenter study on ANCA in NL and BE (with Xavier Bossuyt) is ongoing.

#### **5. How will we go forward with the EASI questionnaire on APS ?**

The APS questionnaire for clinicians was done in Israel and in collaboration with Angela Tincani and Andrea Doria. Results will be presented at the ACLA congress in Brazil (in two weeks). It was not sent to labs.

The group decides to postpone the roll-out of the questionnaire and to discuss further EASI activities on APS at the next forum meeting in Nice. Boris Gilburd has prepared or will prepare a questionnaire for labs. This may be discussed in Nice, too.

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

100 books are brought to the Dresden congress and will be offered to participants of the EASI symposium on September 3<sup>rd</sup>.

The German and Austrian EASI groups have done a German translation which is ready for this congress, too. The book will be introduced to German-speaking congress participants on September 4<sup>th</sup>. It was translated in order to reach the German-speaking doctors more effectively.

Yehuda suggests sending the pdf of the book in a mail with big distribution list. Nina will ask Pabst for the pdf of the whole book (with less than 4 MB). This will be linked on the EASI webpage as well as on the autoimmunity webpage and could be used by EASI groups to send around and to make doctors aware of the book. However, it is strongly recommended not to send the pdf because most people receive today their mails on their phones – where big attachments are bothering. Better send the link.

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

Yehuda proposes to do a digital book as particularly young people will have more access, higher availability and it is less expensive (no print costs). He intends to do a protocol book.

The Spanish group GEAI has done a protocol book. Aresio Plaza will check if the group agrees in translating the book or using parts of it as basis for the international book. He will send around a digital version so that everybody can check it.

Such a protocol book could be helpful for accredited labs. Comparison of methods taken from the literature? Harmonization of lab comments, e.g. definition of high levels and low levels etc.

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

Example in Germany: The group checks articles on autoimmunity in rheumatology sites or at Wikipedia and corrects if there is wrong information. However, Yehuda gets rashes when someone mentions Wikipedia and so we leave this to the local groups.

**9. Next EASI Forum Meeting**

The next EASI Forum meeting will be held attached to the 9th International Congress on Autoimmunity in Nice, May 2014. Nina will clarify the concrete time and place and will invite accordingly. As agreed in Porto, the meeting should be planned for 2 hours minimum, as it fitted very well in this meeting.

Eckart Mummert proposes for the EASI congress to focus on celiac disease. He prepared a possible agenda. However, no EASI members are involved and so the link to the EASI group might be missed. There should be an additional talk such as "Celiac disease and its link to other autoimmune diseases". EASI should be included. Yehuda and Eckart will discuss this in the following.

So far, gastroenterologists are not well represented in EASI. However, the French group has done a questionnaire on Celiac to 700 clinicians (pediatricians, GPs, gastroenterologists). Other EASI groups have started to contact celiac specialists to implement celiac into the EASI group, too.