Minutes EASI Forum

Dresden, October 28, 2017; 12:30 - 14:00 h



Participants:

Chairman: Jan Damoiseaux (NL)

Austria: Günter Steiner Belgium: Xavier Bossuyt

Croatia: Ana Kozmar, Andrea Tešija Kuna Finland: Anna-Maija Haapala, Markku Viander

France: Nicole Fabien, Marie-Agnes Dragon-Durey, Lucile Musset

Germany: Elena Csernok, Ulrich Sack

Greece: Dimitri Bogdanos, Alexandra Tsirogianni

Italy: Nicola Bizzaro

Netherlands: Jan-Willem Cohen Tervaert, Maarten Limper

Poland: Catarzyna Fischer

Portugal: Carlos Dias, Maria José Souza

Russia: Olga Komarova, Olga Kozhevnikova Spain: Ricard Cervera, Marcos López-Hoyos Sweden: Catharina Eriksson, Rille Pulleritz

Brazil: Luis Andrade **USA:** Edward Chan

<u>Thermo Fisher Scientific and HVD</u> (*Distributor of Thermo Fisher Scientific in East Europe*): Nina Olschowka (Global Marketing AI), Jordi Bertran (SP), Felix Gastager (International, HVD), Alexander Hill (RU, HVD), Thomas Horn (AT), Niki Lourou (GR, HVD), Emanuelle Wattez (FR)

Protocol: Nina Olschowka

Agenda:

- 1. Welcome
- 2. ANA and ANCA questionnaires by new EASI teams
- 3. Some selected Local EASI groups present their current topics
- 4. Likelihood-study with dsDNA (and Sm) antibodies
- 5. ISO15189 Summary of the national interpretations/guidelines feedback from countries
- 6. ICAP questionnaire
- 7. New EASI website
- 8. How to organize EASI Forum meetings in the future
- 9. EASI session on myositis
- 10. Next EASI Forum meeting

1. Welcome (Jan Damoiseaux)

Jan Damoiseaux welcomes the 35 participants from 14 different European countries and in particular the representatives from the new EASI groups from Russia, Croatia and Greece and the guests Luis Andrade from Brazil and Edward Chan from the USA.

2. ANA and ANCA questionnaire by the new EASI teams

Some of the new EASI teams (Russia, Croatia, Greece, Estonia, Poland) were not included in the ANA

questionnaire publication (Damoiseaux J et al. Clin Exp Rheumatol 2014;32(4):539-46). Jan proposes that those countries collaborate to publish their results together.

3. Some selected Local EASI groups present their current topics

Beginning with this EASI forum meetings, from now on three to four local EASI teams will introduce their work shortly.

a. Portugal

Maria-José Souza, the "host" of this meeting, introduces the Portuguese team and their work in the past. The presentation is attached to these minutes.

b. Croatia

Andrea Tešija Kuna introduces the very new Croatian EASI team and their work so far. The presentation is attached to these minutes.

c. Netherlands

Jan Damoiseaux introduces the last projects of the Dutch EASI team. Some of them could be copied by the other national EASI teams. If a national team is interested, please contact Jan. The presentation is attached to these minutes.

4. Likelihood-study with dsDNA (and Sm) antibodies

Unfortunately, Ingmar Heijnen from Switzerland could not attend this meeting. However, he had discussed beforehand with Jan Damoiseaux that the approach of likelihood intervals specified for special tests, as introduced by Xavier Bossuyt for ANCA, should be done also for other tests. Particularly of interest is dsDNA antibodies, as this is a very heterogeneous group, giving different results with different methods. Xavier Bossuyt proposes to include Sm antibodies in such a study. Jan Damoiseaux will approach Ingmar Heijnen to discuss with him and Xavier the study protocol. All meeting participants agree that this is a valuable study and that it should be performed by EASI as multicenter study. Jan Willem suggests not to restrict the study to European countries, because this was considered a limitation of the before-mentioned ANCA study. Luis Andrade (Brazil) and Edward Chan (USA) agree to organize a participation of centers in their countries.

5. ISO15189 – Summary of the national interpretations/guidelines – feedback from countries

Ulrich presents the summary of the feedback of the different EASI teams to his question on the national guidelines how to do the ISO15189 certification. His presentation is attached to these minutes. There is a huge overlap between the different countries. Some countries have not given their feedback yet and are asked to do so in the next two to three weeks. Ulrich will merge this and send this to the different national EASI teams. Nina will provide him with a distribution list. The goal are international guidelines in a publication in the Autoimmunity Reviews.

6. ICAP questionnaire

In the last forum meeting, Xavier had presented a Belgian EASI project: The Belgian EASI team has done a digital survey in Belgium for lab professionals and rheumatologists (separately) to find out how the ICAP is implemented and accepted. Xavier had contacted the different national teams with a request for participation and details about how to run this questionnaire. It can be done in all EASI countries, but should be kept digital (electronic) and in English. The EASI teams could offer their help in case of language or interpretation difficulties. Participation is to be initiated via Xavier.

Luis Andrade explains that in Brazil two surveys were performed, one before the ICAP project (this was the initiation of the ICAP project) and one some years later. This gave a good picture how the ICAP recommendations were adapted.

In addition, the Belgian EASI team as designed a questionnaire about technical aspects of the ANA-test. Information obtained may be very helpful for defining test requirements and this will further link to the initiative of Ulrich with respect to guidelines for ISO15189 accreditation. Also, there is clear interest from

the EFLM (European Federation of Laboratory Medicine) to collaborate with EASI on guidelines with respect to autoantibodies. This will be further elaborated upon by Xavier and Jan. Participation to this questionnaire can be initiated via Xavier.

7. New EASI website

On Wednesday, Nina had the final discussion with Karsten Conrad and representatives of the GFID (Gesellschaft zur Förderung der Immundiagnostik e.V., the organizer of the bi-annual Dresden Symposium on Autoantibodies) on the contract for the financial support of the website. The German and Austrian EASI teams will become members of the GFID. The GFID will build a work group for the EASI webpage, which will be fully responsible for the content of the page. Thermo Fisher will support the GFID for building up and taking care of the new website. The name will remain "easi-network.com". We hope that the contract will be signed in the next two weeks and that the building of the new webpage will start immediately afterwards.

Nina will contact the national EASI teams and ask for content of their local subpages (members, contact, publications etc.).

8. How to organize EASI Forum meetings in the future

Nina reports that there is some concern about the independence of EASI from Thermo Fisher Scientific. However, the participants of the meeting agree that Thermo Fisher's role as organizer, supporter and coordinator is useful and should not be changed. There has never been any influence on the content of the EASI projects. Nina and Jan ask all EASI members to be ambassadors for the EASI idea and that they make clear wherever necessary, that Thermo Fisher has no impact on the content of the EASI projects but is a pure coordinator.

Dimitri Bogdanos proposes that Thermo Fisher can organize the meeting and be present, but for special topics, which should be discussed without any industry representatives, the Thermo Fisher and distributor employees will leave the meeting.

In the past, all forum meetings have been organized in conjunction with the International Autoimmunity Congress, with the Dresden Symposium on Autoantibodies or with the CORA. Due to the new MedTech rules, it is not possible that Thermo Fisher invites EASI members to these congresses. However, when Thermo Fisher invites to an own meeting, independent from a 3rd party event, it is possible to invite to this meeting and pay for accommodation and travel expenses. Those meetings could take place in a central town which is easy to achieve, such as Frankfurt, and could take place for a whole day. The meeting participants agree that this was a good solution. Nina will re-check the legal conditions and, if this is agreed by the legal department of Thermo Fisher, she will discuss with the EASI forum members the best date for such an "EASI-forum-day" in early 2019.

However, forum meetings and EASI sessions will further take place at the International Autoimmunity Congresses and the Dresden Symposium on Autoantibodies.

9. EASI Session on Myositis

The EASI Session on Myositis which took place on Friday, May 19th, at this congress was well attended and gave very interesting insights. Yehuda Shoenfeld has proposed to do an EASI manuscript from the session. Jan will take care.

Nina informs that she has visited Fred Miller from the NIEHS (National Institute of Environmental Health Science) who is a well-known specialist on myositis in the US, organizing regular meetings etc. He would be very interested in a collaboration with EASI. Nina will connect Fred Miller with Jan for further collaboration in the topic of myositis. Also Yves Allenbach (France, speaker in EASI session) has asked for collaboration with EASI with respect to myositis. Yves is involved in the French and European myositis networks.

10. Next EASI Forum Meeting and next EASI Symposium

Depending on point 8 of these minutes, the next EASI forum meeting will take place in a town in central Europe, which is easy to travel to.

Still, at the Dresden Symposium in September 2019, an EASI forum meeting will take place. There will also take place an EASI Symposium (EASI Session). The topic of this session will be discussed in the "EASI-forum-day" or by mail.