
Minutes

EASI Forum

Dresden, September 11, 2019; 12:45 – 13:45 h

Moderation: Jan Damoiseaux (President of EASI Forum),

Austria: Manfred Herold, Sonja Jansen-Skoupy
Belgium: Carolien Bonroy, Xavier Bossuyt
Brazil: Luis Andrade, Aline Oliveira
Croatia: Lovorka Đerek, Katarina Gugo
Estonia: Liisa Kuhi, Raivo Uibo
Finland: Hanna Jarva
France: Lucile Musset
Germany: Ulrich Sack
Greece: Dimitrios Bogdanos, Kalliroi Tsialima
Hungary: Péter Antal-Szalmás, Tímea Berki, Gabor Nagy
Italy: Pier-Luigi Meroni
Latvia: Liisa Kuhi
Netherlands: Jan Damoiseaux, Marco Schreurs
Poland: Katarzyna Fischer
Portugal: Maria José Sousa, Esmeralda Neves
Russia: Elena Borzova
Spain: Marcos Lopez-Hoyos
Sweden: Catharina Eriksson, Johan Rönnelid
USA: Ed Chan
East Europe: Felix Gastager

Minutes: Nina Olschowka (Thermo Fisher Scientific, Germany)

Agenda

1. Welcome, introduction round, organizational details
2. Update of the 4th International Autoantibody Standardization (IAS) Workshop from September 9th
3. Website – what is missing and how to proceed
4. Current status of projects, follow-up from our meeting in March:
 - a. ISO 15189
 - b. dsDNA / Sm multicenter study
 - c. Questionnaires on ICAP and on methodologies
 - d. Myositis Network, new recommendations
 - e. Evaluation of Myositis tests
 - f. ANA/ENA recommendations from EULAR - current status and possible collaboration with EASI
5. Discussion: What are our goals for 2020? And beyond?
 - a. Planning of EASI Forum Meeting and EASI Session at the ICA in Athens in May 2020
 - b. 2nd EASI Forum Day in Freiburg in autumn 2020

1. Welcome, Organizational Details

Short introduction round.

Copies of the EASI Books “The General Practice Guide to Autoimmune Diseases” were offered and Nina reminds of the possibility to order copies in Freiburg.

Jan transfers apologizes for the absence of the Swiss EASI team (communicated by Ingmar Heijnen: they had their annual Swiss meeting just the week before the Dresden meeting).

2. Update of the 4th International Autoantibody Standardization (IAS) Workshop

At the IAS Workshop in Dresden on Monday, September 9th, Xavier presented a way how to best address standardization through harmonization of test result interpretation with the help of likelihood ratio. It was discussed that EASI will support this approach by

1. Collecting samples starting with the project on anti-dsDNA antibodies (Xavier will come with instructions and an example for requesting ethical approval)
2. Education of lab and clinicians about the meaning of likelihood ratios and how to use it for a useful interpretation of results. (further follow-up, when data are available)

To Do: Discuss approach in the local teams.

3. EASI Website (<https://www.gfid-ev.de/easi>)

Nina will reach out to Karsten Conrad/ GFID: 1. the site should be available via “easi-network.com”; 2. More modern design. 3. For the forum meeting protocols and attachments, an own site shall be created with password.

To Do: Discuss in local teams which information you want to see on your site and deliver this information either to nina.olschowka@thermofisher.com or to gfid.ev@me.com. Please provide information in English.

4. Current status of projects, follow-up from our meeting in March

a. Quality and Best Practice – Ulrich Sack

As follow-up of the group work in Freiburg, 4 EASI members stayed in discussion and have developed a position manuscript for publication. However, the manuscript is still in progress (some more discussions needed). When finalized, it will be sent to the EASI forum. Publication is planned in Autoimmunity Highlights (Nicola Bizzaro is editor and offered a publication free of charge)

b. dsDNA/Sm study – Xavier Bossuyt

The study will focused on the evaluation of antibody affinity. Additional aims is to look at existing assays; a good collection of samples is necessary – local EASI teams should contribute. Xavier will come with a proposal which samples are needed. Clarification with the ethics committee has to be done in every country, but usually one per country is enough and can be used for other labs. Evidently, the new WHO standard for anti-dsDNA antibodies will be included in the study (recently published in Ann Rheum Dis; Johan Rönnelid as last author).

To Do: Discuss in the local EASI teams who could contribute with samples, which samples are available etc. Discuss, who can take care of the permission of the ethics committee. All to be done only after instructions from Xavier are available.

c. ICAP Questionnaire and Questionnaire on ANA methodology – Xavier Bossuyt

Questionnaires on ICAP and on methodologies; questionnaires are closed and are evaluated currently. First results of the implementation of ICAP were presented at the ICAP workshop on

Monday, September 9 by Lieve Van Hoovels. First results about the methodologies, only from Belgium, are shown on Friday on the congress.

d. **Myositis: new recommendations of the Myositis Network – Carolien Bonroy**

Jan, Lucille and Carolien, together with Yves Allenbach, have contacted Andrew Mammen and Olivier Benveniste from the ENMC (European NeuroMuscular Centre). An application for an ENMC workshop is being prepared in order to enable the organization of a 2-days workshop with 20-25 people (lab people and clinicians). In the afternoon of the second day the intention is to generate an outcome in terms of guidelines.

e. **Evaluation of myositis assays – Xavier Bossuyt**

Xavier and Carolien are working on the meta-analysis of results obtained by line/dotblots. So far, data are available from 3 centers. Likelihood ratios have been evaluated. Study shall be extended.

To do: Please inform local teams: Everybody who wants to contribute should inform Xavier until end of October latest (Xavier.bossuyt@uzleuven.be). Note: only anonymized data can be used! Please state which diagnostic criteria were used.

f. **ANA/ENA Recommendations – Marco Schreurs**

EASI Netherlands has evaluated the compliance of the 15 Dutch ANA testing recommendations by questionnaire. As a result and in compliance with ICAP, the recommendations were revised: 17 newly formulated recommendations, 12 are mandatory, 5 are voluntary. They are currently under review. Next month, the guidelines will be finalized and shall be published in a Dutch journal before the end of the year (local recommendations!).

Long-term goal: EASI countries should do a questionnaire on the EASI recommendations and maybe do a revision. However, the group agreed that it makes sense to wait for Pier-Luigi's meta-analysis on ANA testing and the resulting EULAR recommendations.

g. **Harmonize the nomenclature in rheumatic diseases – Jan Damoiseaux**

Goal: create a glossary so that all institutions use the same language. Definition of terms in systemic autoimmune rheumatic diseases, what is ANA, what is ENA, SARD, AARD, CTD....

Collaboration with ICAP. Jan proposes to use Delphi score system to define which definitions should be used. List shall be ready before the finalization of EULAR recommendations.

To Do: Discuss in local teams, which terms should be included and which term you would prefer (with pros and cons). Please send list to Jan Damoiseaux (jan.damoiseaux@mumc.nl) until end of October.

5. **Discussion: What are our goals for 2020? And beyond?**

a. **EASI at the ICA in Athens in May 2020**

Nina will reach out to Sari from Kenes for time and place of the EASI Forum Lunch meeting

Jan and Xavier will make a proposal for the agenda of the EASI Session and communicate it as soon as possible to Kenes/Yehuda Shoenfeld. Topic: Standardization through harmonization of test result interpretation (see point 2 of this agenda)

b. **2nd EASI Forum Day in Freiburg in autumn**

Nina will organize a whole-day-meeting in Freiburg, Germany in autumn 2020. Like the meeting in Freiburg in March 2019, it will be a follow-up of projects and intense workshops to proceed in our projects.

c. **Questions from the Forum-members**

Ed Tan thanked EASI for the active contribution to the ICAP page (translations). Marie-Jose proposed that EASI could take part in the consensus on ANA reporting as being prepared by ICAP. Although reporting of autoantibody results is a topic to be addressed by EASI, we are currently not in the position to ask for participation in the ICAP initiative because this may cause too much delay on their site.