

Meeting Report

EASI Forum

Dresden September 23rd, 2011

Participants: Aresio Plaza (E), Ulrich Sack (D), Lucile Musset (F), Nicole Fabien (F), Manfred Herold (A), Günter Steiner (A), Pier-Luigi Meroni (I), Carlos Dias (P), Maria José Sousa (P), Jan Damoiseaux (NL), Walter Fierz (CH), Catharina Eriksson (SE), Olof Hultgren (SE), Markku Viander (FIN), Marja Hietarinta (FIN), Yehuda Shoenfeld (ISR), Nancy Agmon-Levin (ISR),

Guests: Carmen Andalucia (E), Gerben Zuiderveld (NL), Udo Schlosser (D), Teresa Araujo (P), Sune Sved (FIN), Monika Snor (A), Gunnel Jansson (SE), Lilian Larsson (SE), Nina Olschowka (D)

Protocol: Michael Haass (D)

Agenda

1. Get together and lunch
2. Status of the EASI Projects
 - b. EASI Family Doctors Booklet
 - c. EASI surveys (Laboratory survey based on the Dutch Questionnaire; Clinical Questionnaire)
3. Positioning paper of the EASI Steering Group together with the EASI Forum how CTD Diagnosis should be supported in Europe
4. New projects
5. Next EASI Conference in Granada (Topic: Diagnosis of ANCA associated Vasculitis, incl. feedback from the Chapel Hill meeting 2011; proposal of a program)
6. Next EASI Forum
7. End of the meeting

Discussion Topics and Decisions

1. Get together and lunch

After welcoming the participants and presenting the agenda of the meeting, Michael informed the attendees that the takeover of Phadia through Thermo Fisher Scientific will not influence the collaboration between the new company and the EASI network. Phadia builds now the new ImmunoDiagnostics Division of Thermo Fisher Scientific and will continuously fully support EASI.

2. Status of the EASI Projects

a. *Booklet for Family Doctors*

The preparation of the booklet is finalized. All chapters have been prepared.

To update those chapters which have been sent a long time ago, Nina will send the chapters back to the authors. Please, update the references so that at least one of them is from 2010 or 2011. Please, make sure too that only 5 references will be included.

Please, send the chapters back to Nina (nina.olschowka@thermofisher.com) not later than Sunday, October 16.

The chapters will be finally reviewed by Yehuda Shoenfeld and thereafter sent to the publisher for publication.

Aim is to distribute the booklet at the Granada Congress in May 2012.

b. *EASI ANA surveys in Europe (ANA questionnaire I to Laboratory Specialists; ANA questionnaire II to Clinicians)*

A summary of the collected data for the ANA Laboratory Survey has been presented by Nina (see presentation attached).

Unfortunately, not all EASI countries have performed this survey so far. All the countries are invited to complete the evaluation of this ANA Laboratory Survey to get a most complete picture of the European situation. Nina and Jan will collect and summarize all the data from the different countries and Jan will present the data at the Granada Congress in May 2012. Furthermore, it is planned to write a publication. Of course, this is only interesting when most of the European countries are involved.

A second ANA questionnaire for Clinicians has been created by the EASI groups in Portugal and Finland. Also here, all other countries are invited to participate in this survey too.

Again, the more countries will use this questionnaire the better the information we can gather about the usage of ANA in clinical practice in Europe and the more attractive are the data for follow-up projects and publication.

Both questionnaires are attached to this protocol.

To enable a final analysis of the data on a national and European level, the questions of both questionnaires should not be modified.

If mistakes are identified, please, get in touch with Nina (nina.olschowka@thermofisher.com).

If you like to shorten the questionnaire, the number of questions in the questionnaire can be reduced. If countries would like to have more information about their countries, questions might be added individually.

3. Positioning paper of the EASI Steering Group together with the EASI Forum how CTD Diagnosis should be supported in Europe

Nancy presented the analysis of the discussion about the ACR recommendation and the comments most EASI countries have given to the statement paper Nancy, Jan, Pier-Luigi and Yehuda have sent (see original statements and presentation attached to this report).

For different reasons, not all EASI countries have participated in the discussion about the recommendations, yet. The missing countries are asked to send their comments as soon as possible to Nancy (nancy.agmon-levin@sheba.health.gov.il).

Some open issues which need to be solved before a final paper can be prepared, were highlighted. It is required to discuss these issues more in detail and find a final agreement. Nancy and Jan will distribute these issues again, partly with new proposals. Please, send your comments as soon as possible to Nancy (nancy.agmon-levin@sheba.health.gov.il).

4. New projects

The group decided not to start new projects before the ongoing ANA projects and the Family Doctors Booklet have been finalized.

At the next EASI Forum in Granada this topic will be discussed again.

5. Next EASI Conference in Granada (Topic: Diagnosis of ANCA associated Vasculitis, incl. feedback from the Chapel Hill meeting 2011; proposal of a program)

The proposal for the EASI Conference in Granada is to focus on ANCA associated diseases.

The agenda below was presented.

Title: **ANCA-associated diseases**

Lectures

Chairmen: Y. Shoenfeld

16:00 A. Vaglio – “ANCA-testing from the perspective of the clinician”

16:20 J. Charles Jennette – “New Diagnostic Criteria of ANCA-associated vasculitis”

16:40 Charles Pusey – “How are anti-GBM to be included in ANCA testing?”

17:00 Jan Damoiseaux – “How are ANCA tested in specialized labs – is there a need of standardization? – Results of the EASI questionnaire on ANCA”

17:20 Nils Rasmussen – “Optimum Approaches to Clinical ANCA Testing”

Round table discussion:

Chairman: J.W. Cohen-Tervaert

17:40 ANCA on the way to become diagnostic criteria

PR3 and MPO measurement with IIF, with EIA or both? What is the gold standard of ANCA testing?

After a short discussion the group agreed to follow the proposal.
Michael will start to invite the speakers and organize the session.

6. Next EASI Forum Meeting

To intensify the discussion about the EASI projects, in particular about the Positioning paper, the group agreed on meeting the next time in Porto at the Portuguese Autoimmunity congress, which is planned to be held in February 2012.

Carlos Dias will inform the members of the EASI Forum about the exact dates and program of the congress. All would appreciate if the time slot for the EASI meeting could be a bit longer so that we have time to discuss and finalize the positioning paper.

Freiburg, September 28th, 2011

Michael Haass

Attachments:

- Nina's presentation: EASI Questionnaire to evaluate ANA ENA testing in Europe
- Nancy's presentation: EASI initiative - European Standardization of ANA detection
- EASI ANA surveys in Europe
 - ANA Questionnaire I to Laboratory Specialists
 - ANA Questionnaire II to Clinicians
- Positioning paper of EASI how CTD Diagnosis should be supported in Europe (1st version)

APPENDIX

SUMMARY TO DO's

- **Booklet for Family Doctors**
 - Nina: Please, send the chapters back to the authors.
 - All authors: Please, rework the chapters, update the reference list if required (5 references, 1 from 2010/2011) and send the chapters back to Nina (nina.olschowka@thermofisher.com) no later than Sunday, October 16.
 - Yehuda: Please, finally review the chapters
 - Michael: Please, send the booklet to the publishers.
 - Launch of the booklet at the Autoimmunity Congress in Granada in May 2012.

- **EASI ANA surveys in Europe**
 - All countries: Please, complete the evaluation of the ANA Questionnaire I to Laboratory Specialists as soon as possible.
 - All countries: Please, distribute the ANA Questionnaire II to Clinicians, collect the data and send the data to Nina for evaluation.
 - All countries: Please, do not modify the individual questions.

- **Positioning paper of EASI**
 - All countries that have sent their comments yet: Please, send your comments as soon as possible to Nancy (nancy.agmon-levin@sheba.health.gov.il).
 - Nancy and Jan: Please, distribute these positioning paper and questions about the particular topics again.
 - All countries: Please, send your comments as soon as possible to Nancy (nancy.agmon-levin@sheba.health.gov.il).

- **EASI Conference in Granada**
 - Michael: Please, start to invite the speakers and organize the session.

- **Next EASI Forum Meeting**
 - In Porto during the Portuguese Autoimmunity Congress in February 2012.
 - Carlos Dias: Please, inform the members of the EASI Forum about the exact dates and program of the congress.
 - All countries: Please, block your agendas accordingly.