

Meeting Report

EASI Forum

Sorrento, November 29, 2006



Participants: Allan Wiik (DK), Ricard Cervera (E), Aresio Plaza (E), Ulrich Sack (D), Xavier Bossuyt (B), Lucile Musset (F), Nicole Fabien (F), Walter Fierz (CH), Stephan Regenass (CH), Marrku Viander (FIN), Manfred Herold (A)

Phadia: Michael Haaß (D), Dietmar Germadnik (A), Walter Ineichen (CH), Carmen Andalucia (E)

Guest: Jan Meyrowitsch (DK)

Protocol: Michael Haaß

Discussion Topics and Decisions

Yehuda Shoenfeld, the new Chairman of the EASI Core Group

Allan Wiik decided to step back from the chairmanship of the EASI Core Group. He is retiring from his position in the Statens Serum Institute and going to focus more on his private life. Allan Wiik will remain a member of the EASI Core Group and continuously support the initiative.

Presentations of the EASI Projects proposed by the EASI Core Group for 2007

1. Publication of the guidelines for family doctors

To finalise the EASI Core Group activities of the last years, the EASI Core Group will publish the screening algorithm for family practitioners in one of the international family practitioner journals.

Next Step: Allan Wiik will write the paper; Yehuda Shoenfeld and the other EASI group members will review it.

2. Booklet(s) for family doctors

A booklet for family practitioners will be written in a joint project for all EASI teams. Authors from the different EASI teams will write in a joint collaboration the chapters of the booklet, covering one of the rheumatic / autoimmune diseases. Beside the EASI Team members also external collaborators are welcome to join the EASI authors.

The booklet(s) should cover all areas in Autoimmunity. Each of the chapters will focus on one disease and on the symptoms of the different disease phenotypes, recommend markers, which can help to make the right diagnosis and phenotype and describe algorithms that are recommended for use.

It is important that the booklet describes very practical approaches in a condensed way and a very clear language. The focus of all articles shall be on early diagnosis of the diseases.

The structure of each chapter of the booklet will be the following:

- Introduction
- Table with signs and symptoms and frequency of the disease

- One illustrative picture (clearly showing the characteristic presentation of the disease)
- Diagnostic criteria (criteria in form of two tables)
 - Clinical and
 - Laboratory
- Diagnostic measurements for experts
- Requirements for family practitioners (larger chapter)
- Follow up
 - Clinical observations,
 - Expectations,
 - Blood tests to be done
- Management (therapeutic principles)
- Diagnostics tests
 - Short description,
 - Pictures or diagram
- Testing methods
 - Benefits
 - Limitations
- References (max. 5 references: 2 reviews, 2 original papers, one reference to management principles)

The authors from the different EASI teams should provide the article to the editorial board: Yehuda Shoenfeld, Allan Wiik, Pier-Luigi Meroni, Ricard Cervera, Michael Haass.

The leading author should be a clinician.

Deadline for all articles is the International Autoantibody Symposium in Dresden in 2007.

Instructions to the authors will be sent out by Yehuda Shoenfeld and Allan Wiik.

A list with the diseases the booklet(s) should cover, incl. the authors identified so far, is attached at the end of this minutes.

Next Steps:

- With the minutes of the meeting Michael Haass will send a list with diseases and already identified authors for reviewing to Yehuda Shoenfeld and Allan Wiik.
- The list will be send with the minutes of the EASI Forum to the attendees of the EASI Forum. Michael will collect the feedback about the additional authors (names and addresses) and send the list to Yehuda Shoenfeld and Allan Wiik.
- Both will prepare a letter with instructions and send it directly to the authors.

3. Multicentre Study

A multicentre study about the performance of the different methods used for autoantibody testing should be initiated. All assay systems, which are commercially available, should be included.

The study should be run in cooperation with IUAS, if this group agrees on the cooperation.

The study should be divided into

- a. A routine study with samples randomly selected by the laboratories from their daily practice (5000 samples collected by the Nordic group might be used for this part of the study)
- b. Clinical study with samples from clinically well defined samples provided by different centres of the different EASI groups (sample volume min 5ml). All samples will be collected following the required ethical regulations.
- c. Control samples (blood donors and disease samples from non autoimmune diseases).

All samples should be collected by the members of the different EASI teams. The samples should be sent to the Statens Serum Institute in Copenhagen, Denmark, where they will be collected and coded. From here the samples will be sent to the manufacturers.

All manufacturers will be invited to a meeting in Spring 2007 by Pier-Luigi Meroni to explain the concept of the study and to invite them to participate.

Each manufacturer, who agreed to attend the study, will get a set of coded samples to identify the autoantibody specificities in the samples. The results should be sent to the organisers for further analysis.

The results of the study will be published without presenting the names of the manufacturers.

The projects listed above were also presented to and discussed with the EASI Forum

They are aiming for a closer cooperation between the different EASI teams.

Next Steps:

- Discussion with IUAS whether a combined study should be run.
- Definition of the study concept.
- Invitation of the companies to present the concept and to identify which companies would be interested to participate.

Additional projects the EASI Forum members are interested in

- Preparation of a recommendation how new tests should be evaluated clinically.
- Creation of a database with data how the different test systems available in the market have been evaluated. In this project the manufacturers should be asked to describe how their assays have been evaluated. The results should be collected in a database format.
- Analysis of the pre-test probability (What probability does a particular symptom provide for the disease diagnosis ?). The Belgian and Swiss EASI teams announced their interests in a collaboration in this topic.
- More frequent usage of PPV, NPV or likelihood ratios in addition to prevalence, sensitivity and specificity in assay evaluations.
- Collection of country specific test algorithms, which will be presented and discussed at the next Forum.

Presentation of WiseCase – A mind bridging solution to globalize expertise in Autoimmunity

Jan Meyrowitsch presented a new software tool for a Web-Interacting Standardisation in Expert Classification Agreement by Statistical Evaluation, which actually is set-up for the education of specialists in the area of IFA. The software tools are working online in restricted intranet based on granted permissions. The approach is very open and can easily be used for all other areas that need the interaction of specialists and/or users. With this approach to global knowledge networking WiseCase is an interesting tool to support the ideas of EASI.

For more information Jan Meyrowitsch can be contacted under www.percepton.com.

Next EASI Froum Meeting

The next EASI Forum Meeting will be held attached to the Dresden Autoantibodies Symposium in September 2007

Freiburg, December 20th, 2006

Michael Haass

Appendix

Systemic Rheumatic Autoimmune Diseases

19.12.2006

Addison's Disease	
Primary Anti-Phospholipis Syndrome / Hughes Syndrome	M Khamashta
Polymyositis	
Dermatomyositis	
Myositis Overlap Syndrome	
Systemic Sclerosis / Scleroderma	PL Meroni
CREST Syndrome	
Sjögren's Syndrome	PL Meroni
Vasculitis ANCA associated	A Wiik
Microscopic Polyangiitis / Churg Strauss Syndrome	
Wegner's Granulomatosis	
Goodpasture Syndrome	
Vasculitis non ANCA associated	A Wiik
(Lupus Vasculitis, Rheumatoid Vasculitis)	
Behcet's Syndrome	Shoenfeld / Krause / Jasiki
Systemic Lupus Erythematosus	R Cervera
Discoid Lupus Erythematosus	
Subacute Cutaneous Lupus Erythematosus	
Neonatal Lupus / Congenital Heartblock	
Mixed Connective Tissue Diseases	
UCTD	Stefano
Myasthenia Gravis	
Autoimmune Gastritis	
Pernicious Anemia	
Pemphigus Vulgaris	
Pemphigus Foliaceus	
Bullous Pemphigoid	

Primary Billiary Cirrhosis	
Primary Sclerosing Cholangitis	
Rheumatoid Arthritis	A Wiik, G Steiner
Felty's Syndrome	A Wiik
Psoriatic Arthritis	
Juvenile Rheumatoid Arthritis	
Lyme Arthritis	
Diabetes Mellitus	
Inflammatory Bowel Diseases	
Colitis Ulcerosa	
Morbus Crohn / Crohn's Disease	
Celiac Disease	
Autoimmune Thyroid Disease	
Graves Disease	
Morbus Basedow	
Autoimmune Hemolytic Anemia	
Autoimmune Thrombocytopenia Purpura	
Autoimmune Myocarditis	
Multiple Sclerosis	
Guillain-Barré Syndrome	
Fibromyalgia	Y Shoenfeld
Chronic Fatigue Syndrome	
Polychondritis	JC Piette