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Introduction
About the Lupus Academy
What is the Lupus Academy?

The Lupus Academy is a long-term initiative committed to improving patient outcomes in SLE and allied diseases. By providing a highly interactive educational forum, the Lupus Academy is dedicated to sharing best clinical practice through the dissemination and discussion of cutting edge scientific and clinical research.

The Lupus Academy is a Consortium consisting of the Academic Steering Committee and the support organisations. The organisation is a tax entity acting as a partnership.

All activities are independently developed and controlled and CME accredited where possible and appropriate.
The Steering Committee was extended with the following new members at the 2nd Meeting:

Three further members, from North America, will be announced in 2014.
Approach to content and format

**Clinical Practice**

- Morbidity and Mortality
- Biologics
- Infection
- Pregnancy and APS
- Improving CV Outcomes

**Basic Science**

- Genetics
- T-Cell Signalling
- Immuno-pathogenesis

**Workshops**

- Biologics
- Lupus Nephritis

**Clinical Practice**

- Fatigue
- Cutaneous SLE
Barcelona 2012
Report from the 1st Annual Meeting
Inaugural Meeting of the Lupus Academy

• 16-18 March 2012, Barcelona
• Faculty: 17 international experts in Lupus, 5 of whom were members of the Lupus Academy Steering Committee
• CME accredited by EACCME for 9 Credits
• Programme format
  • Friday early evening start followed by a 1.5 day meeting
  • 15 didactic presentations
  • 4 parallel workshops with interactive voting, repeated morning and afternoon for participants to be able to attend 2
• Full programme of this meeting is separately attached
• Participants: 296 from Europe, Americas and Asia Pacific
• For educational materials, event film and interviews with the Steering Committee go to: http://www.lupus-academy.org/Login (username: BCN1603, password: %lupus2082)
Delegate Profiles
Country of Origin

- Spain: 60 delegates
- Italy: 40 delegates
- Germany: 30 delegates
- France: 20 delegates
- Portugal: 10 delegates
- Netherlands: 5 delegates
- Rest of World: 5 delegates
- Czech Republic: 10 delegates
- Poland: 5 delegates
- Bulgaria: 5 delegates
- Greece: 5 delegates
- Slovenia: 5 delegates
- Sweden: 5 delegates
- Denmark: 5 delegates
- Hungary: 5 delegates
- Israel: 5 delegates
- Latvia: 5 delegates
- Romania: 5 delegates
- Russia: 5 delegates
- Serbia: 5 delegates
- Slovakia: 5 delegates
- Turkey: 5 delegates
- Austria: 5 delegates
- Belgium: 5 delegates
- Ireland: 5 delegates
- Macedonia: 5 delegates
- Republic of Moldova: 5 delegates
- Norway: 5 delegates
- Switzerland: 5 delegates

Number of Delegates
Specialty and Experience

**Specialty**
- Clinical Immunology: 34%
- Dermatology: 2%
- Internal Medicine: 13%
- Rheumatology: 7%
- Nephrology: 2%
- Other: 42%

**When did you become a specialist?**
- 1980 - 1985: 12%
- 1986 - 1990: 7%
- 1991 - 1995: 5%
- 1996 - 2000: 9%
- 2001 - 2005: 15%
- 2006 - 2011: 26%
- I am not a specialist: 26%

*Lupus Academy*
Communicate. Educate. Treat.
Delegate Feedback – General

• Delegates were asked to provide rated and specific feedback on each presentation/workshop they attended
• 296 delegates attended the meeting sessions: ~65% gave feedback
• Delegates regarded the meeting as a success with the vast majority of delegates (>95%) stating:
  • Overall learning objectives were met
  • There was an absence of commercial bias
  • That they prefer independent meetings over those organised by pharmaceutical companies
• Individual faculty presentations and workshops were also rated very highly.
Content: >95% of delegates agreed with the following statements:

- I prefer independent meetings like this compared to those organised by pharmaceutical companies: 73% Strongly Agree, 22% Agree.
- Avoided commercial bias or influence: 69% Strongly Agree, 27% Agree.
- Handout material was useful: 57% Strongly Agree, 38% Agree.
- Sufficient time for questions and answers: 62% Strongly Agree, 36% Agree.
- Stimulated my intellectual curiosity: 78% Strongly Agree, 20% Agree.
- Will help me to improve patient care: 67% Strongly Agree, 31% Agree.
- Relevant to my practice: 62% Strongly Agree, 37% Agree.

Delegates (%); n=179
Objectives: 99% of delegates said the objectives of this meeting were met to some degree:

- **Provide updates in selected topics in Lupus, and in ground-breaking science and clinical practice:**
  - Fully Met: 71%
  - Mostly Met: 25%
  - Partly Met: 4%
  - Not Met: 4%

- **Provide a platform for the discussion of new ideas:**
  - Fully Met: 64%
  - Mostly Met: 29%
  - Partly Met: 6%
  - Not Met: 6%

- **Challenge current thinking in Lupus:**
  - Fully Met: 68%
  - Mostly Met: 26%
  - Partly Met: 5%
  - Not Met: 5%
Logistics: >95% of delegates agreed with the following statements:

- Overall logistics and administration: 86% Very Good, 14% Poor
- Group food functions, including off-site dinner: 76% Good, 19% Fair, 14% Poor
- Accommodation: 83% Good, 16% Fair
- Meeting rooms and audiovisual: 86% Good, 13% Fair
- Hospitality and registration onsite: 87% Good, 10% Fair
- Communications and logistical arrangement handling from the moment of registration: 90% Good, 9% Fair
- Lupus Academy website and registration: 85% Very Good, 14% Poor
Some Delegate Comments

• Outstanding meeting. Well done!
• High quality content and speakers
• Far better than BSR for update on Lupus related topics
• Very good conference, well organized and will help me give the patients I see the best possible care I can
• Please organize this on an annual basis as it is one of the best meetings I have attended on SLE
• Fantastic communications and logistics
• Better balance of clinical and basic science related talks needed
• Later start of programme with more case discussions
• More data on paediatrics needed
• Would be better to include discussion after each presentation, rather than each session.
# Delegate Feedback – CME

## Overall

<table>
<thead>
<tr>
<th></th>
<th>Extremely Useful</th>
<th>Useful</th>
<th>Fairly Useful</th>
<th>Not Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Overall, what was your impression of this event?</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>156</td>
<td>51</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

## 2. What was your overall impression of the event in respect of:

<table>
<thead>
<tr>
<th></th>
<th>Very good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Quality of content</td>
<td>162</td>
<td>45</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Quality of speakers</td>
<td>160</td>
<td>47</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Organisation</td>
<td>186</td>
<td>21</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Appropriateness of the location</td>
<td>167</td>
<td>41</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sufficient time for questions and answers compared to other meetings</td>
<td>148</td>
<td>52</td>
<td>7</td>
<td>1</td>
</tr>
</tbody>
</table>

## Additional Feedback

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>A little</th>
<th>Not really</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you learned something from this event?</td>
<td>182</td>
<td>25</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Will this event change your practice?</td>
<td>193</td>
<td>62</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>
### Perception of commercial bias

5. Did you feel that there was any bias during the event (please select one only).

![Bar chart showing perceptions of commercial bias](chart)

<table>
<thead>
<tr>
<th></th>
<th>United Kingdom</th>
<th>Spain</th>
<th>Italy</th>
<th>Portugal</th>
<th>France</th>
<th>Germany</th>
<th>Rest of Europe</th>
<th>Americas</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>38</td>
<td>30</td>
<td>19</td>
<td>16</td>
<td>12</td>
<td>7</td>
<td>39</td>
<td>5</td>
<td>31</td>
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<tr>
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<td>0</td>
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<td>0</td>
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<td>0</td>
</tr>
<tr>
<td>Yes: Professional</td>
<td>0</td>
<td>0</td>
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<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Yes: Personal</td>
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<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
2nd Annual Meeting of the Lupus Academy

- 17-18 April 2013, Buenos Aires held in collaboration with the 10th International Congress on SLE
- Faculty: 24 international Lupus experts, 5 from Steering Committee, 6 from SLE Congress Organisers and/or GLADEL Group
- CME accredited by EACCME for 8 Credits
- Programme format
  - Early Wednesday evening start followed by a full day programme
  - 8 didactic presentations
  - 4 parallel workshops with interactive voting, repeated morning and afternoon of day
- Full programme of this meeting is separately attached
- Delegates: 185 from Europe, Americas and Asia Pacific
- Educational and other post-event materials available on website later this summer.
Meeting Objectives
To facilitate improvement in clinical practice and patient outcomes through:

• Improved understanding of the genetic and cellular mechanisms involved in the pathogenesis of lupus
• Discussion of patient perspectives on the burden of lupus and how best to manage this burden to improve patient outcomes.
• Review of recent evidence that affects the positioning of the various treatment options including current and future treatment options available for SLE.
• Better understanding of the issues of cardiovascular, renal and cutaneous manifestations in lupus.
• Greater appreciation of the risk factors for infection, especially with steroid use, and infection prevention measures including steroid-sparing effect of hydroxychloroquine and biologics.
• Understanding and minimising risk associated with pregnancy in the SLE patient.
Delegate Profiles
Country of Origin – Grouped by Region

- Latin America: 51%
- Europe: 35%
- Asia Pacific: 6%
- North America: 7%
- Middle East & Africa: 2%

Lupus Academy
Communicate. Educate. Treat.
Specialty and Experience

**Specialty**
- Rheumatology: 80%
- Internal Medicine: 10%
- Clinical Immunology: 4%
- Dermatology: 1%
- Nephrology: 1%
- Other: 4%

**When did you become a specialist?**
- Before 1980: 13%
- 1980 - 1985: 12%
- 1986 - 1990: 6%
- 1991 - 1995: 13%
- 1996 - 2000: 11%
- 2001 - 2005: 13%
- 2006 - 2012: 12%
- I am not a specialist: 20%
Delegate Feedback – General

• Delegates were asked to provide rated and specific feedback on each presentation/workshop they attended
• 185 delegates attended the meeting sessions: ~40% gave feedback
• Delegates regarded the meeting as a success with the vast majority of delegates (>95%) stating:
  • Overall learning objectives were met
  • There was an absence of commercial bias
  • That they prefer independent meetings over those organised by pharmaceutical companies
• Individual faculty presentations and workshops rated very highly.
Content: >90% of delegates agreed with the following statements:

- I prefer independent meetings like this compared…
- Avoided commercial bias or influence
- Handout material was useful
- Sufficient time for questions and answers
- Stimulated my intellectual curiosity
- Will help me to improve patient care
- Relevant to my practice

Delegates % (n=70)

- Strongly Agree
- Agree
- Strongly Disagree
- Poor
Objectives: >99% of delegates agreed the meeting objectives were met:

- Provide updates in selected topics in Lupus, and in ground-breaking science and clinical practice: 72% Fully Met, 28% Mostly Met
- Provide a platform for the discussion of new ideas: 72% Fully Met, 26% Mostly Met
- Challenge current thinking in Lupus: 72% Fully Met, 28% Mostly Met
Logistics: >95% of delegates agreed with the following statements:

<table>
<thead>
<tr>
<th>Service</th>
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<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall logistics and administration</td>
<td>81%</td>
<td></td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Ground transportation</td>
<td>75%</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accommodation</td>
<td>82%</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meeting rooms</td>
<td>80%</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospitality and registration onsite</td>
<td>82%</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communications and logistical arrangement...</td>
<td>82%</td>
<td>14%</td>
<td></td>
<td>18%</td>
</tr>
<tr>
<td>Lupus Academy website and registration</td>
<td>82%</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Some Delegate Comments

- Excellent meeting, academic content, organisation and facilities
- Biologics plenary presentations (Professors Isenberg and Merrill) could have had more air time as two separate talks
- Provide meeting summary slides/report and PDF copies of the presentations
- There should be more meetings like this, particularly those that are independent from industry
- Interactive case-based workshops provided a good platform for translating and exchanging practical clinical experiences.
## Delegate Feedback – CME

### Overall

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<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>75</td>
<td>23</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
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<td><strong>2. What was your overall impression of the event in respect of:</strong></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Quality of content</td>
<td>79</td>
<td>20</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Quality of speakers</td>
<td>78</td>
<td>22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Organisation</td>
<td>84</td>
<td>13</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Appropriateness of the location</td>
<td>80</td>
<td>18</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Sufficient time for questions and answers compared to other meetings</td>
<td>67</td>
<td>26</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
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<td><strong>Have you learned something from this event?</strong></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Will this event change your practice?</strong></td>
<td>65</td>
<td>32</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>
Perception of commercial bias

5. Did you feel that there was any bias during the event (please select one only).
Objectives for 2014

• Securing increased funding through co-sponsorship
• To present the 3rd Annual meeting (Berlin, 7-9 March 2014)
• To create further activities to turn Lupus Academy into a more widely recognised and sustainable initiative:
  • A “mini-Academy” at APLAR (Philippines, 1 April 2014) – content from annual meeting adjusted to the predominantly Asian audience.
• Create a sustained programme of educational support materials:
  Outputs from educational events:
  e-learning to support educational needs throughout the year
  Act as a needs assessment for future programmes.
A note on co-sponsorship

• To seek “like-minded” co-sponsoring companies
• Critical it is under “proper” CME conditions with arm’s length funding
• Not to have too many companies involved e.g. 3 or 4
• Stipulations:
  • Equal opportunities (a shared journey)
  • Transparent costs (according to commonly agreed standards)
  • Public disclosure of financial support on all materials
  • Direct payment to Consortium with no third-party routes
  • Documentation according to commonly agreed structure
Educational support programme

• Newsletter (3-4 per year) – the first newsletter can be downloaded from www.lupus-academy.org.
• Highlight reports (post-meetings) – Barcelona highlight report is available online, under “Past Events”
• Online post-meeting presentation slides, if sufficient funding
  For download by delegates for information
  For further dissemination of educational messages
• E-learning courses
  If sufficient funding: a University-endorsed Masters programme
• Clinical practice audit (starting 2014)
  Database started, extent of programme funding dependent
• Website update
  Only where needed e.g. for database functionality.
Budget overview

• Annual meeting – 7-9 March 2014
  • 300 attendees, 2 day programme (same format as Barcelona)
  • Estimated costs: €750,000
• Mini-Academy (working title, name to be defined) – 1 April 2014
  • 200 attendees, 1 full day programme, content almost verbatim from annual meeting
  • Estimated costs: €200,000
• Educational support materials – current preferred activities estimated at €250,000 – €450,000

• Total Lupus Academy budget range for 2014: €1,200,000 to €1,600,000
• We are asking companies to provide €450,000 each
Contact Information

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