FH Studies Collaboration Lecturers at the European Society of Atherosclerosis Congress 2015

Pre- and Post- Event Questionnaires

83rd European Atherosclerosis Society (EAS) Congress
Glasgow, UK. March 2015
The information on these slides is intended for educational purposes only. Nothing in these slides is intended to provide specific medical advice nor to indicate or endorse any treatment, action or refraining from action.
• How do we raise public/clinician awareness to the contemporary burden of FH, and the consequences of under-diagnosis or under-treatment?

• What are the impediments to optimum management of FH patients, and how these may be overcome (either through consensus or through customised approaches)?

• How do we promote a uniform, evidence-based standard of care for FH, including genetic counselling and testing as well as timely referral for specialist advice?

• How do we encourage primary care physicians in particular to contribute actively to the management of subjects with FH?

• What lessons can be learnt from successes and failures of patient advocacy in eliciting change from different countries?
How might current patient advocacy groups share their experience and knowledge with countries who have yet to develop such organisations across EAS member countries and beyond?

How can the EAS work together with different patient advocacy groups to enhance cohesion and coordination?

Who are key stakeholders beyond the patient advocacy groups, academic community and industry that we need to work with and is their prior evidence of successful engagement with for instance governments (e.g. Uruguay)?

How can patient advocacy groups help with the dissemination of new data and support the EAS FHSC?
# EBAC Accredited Programme

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.00-10.20</td>
<td>Aims and objectives of the EAS FHSC and the FHSC survey</td>
<td>Prof Kausik Ray, UK</td>
</tr>
<tr>
<td>10.20-10.30</td>
<td>The potential and limitations of historical data- using UK as an exemplar</td>
<td>Dr Handrean Soran, UK</td>
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<tr>
<td>10.30-10.40</td>
<td>The Ten Countries Study – What’s happening in the Asia Pacific Region and synergy with the FHSC</td>
<td>Prof Gerald Watts, Australia</td>
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<tr>
<td>10.40-10.50</td>
<td>What worked well with the Dutch Database and what we are doing differently for the HoFH database</td>
<td>Prof Kees Hovingh, The Netherlands</td>
</tr>
<tr>
<td>10.50-11.00</td>
<td>Getting started in your region</td>
<td>Prof Kausik Ray, UK &amp; Prof Alberico L. Catapano, Italy</td>
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<tr>
<td>11.00-11.15</td>
<td>Data collation and National governance</td>
<td>Prof Kausik Ray, UK</td>
</tr>
<tr>
<td>11.15-11.25</td>
<td>Engaging with governments- how to get genetic screening into law</td>
<td>Dr Mario Stoll, Uruguay</td>
</tr>
<tr>
<td>11.25-11.40</td>
<td>Q&amp;A to all speakers</td>
<td></td>
</tr>
<tr>
<td>11.40-11.45</td>
<td>Next steps</td>
<td>Prof Kausik Ray, UK</td>
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</tbody>
</table>
FH Studies Collaboration: Symposium at EAS 2015

Sunday March 22, 2015, Scottish Exhibition & Conference Centre (SECC), Glasgow, UK

- How common is FH and how is it managed in different parts of the world?
- What are the implications of the current clinical practice on cardiovascular disease?
- Why is high quality prospective data needed and what are the limitations of prior data?
- How to establish new registries of FH and how to get started.
- What are the ethical concerns and governance around data collection on FH?
- How can the FH registry be used locally to leverage public health policy in each region?
Welcome to the EAS Annual Congress 2015 and our special symposium on Familial Hypercholesterolaemia (FH). We would be grateful if you could spare a few moments to answer the following questions on this topic before attending our symposium.

Your responses will be pooled (anonymously) with those of other delegates to generate summary data regarding the knowledge, attitudes and practices of physicians involved in the care of this condition. Kindly note that we intend to follow this up with another brief questionnaire after the symposium – we would be most grateful for your responses at that stage as well.

On behalf of the entire Organizing Committee and supporting staff, I would like to thank you for your patronage and hope that you very much enjoy the deliberations at this unique symposium.

With best wishes,

Professor Kausik Ray
Lead EAS FH Studies Collaboration

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### Pre-Symposium Questionnaire

**About you**

Your answers will remain anonymous.

1. Which most closely approximates to your specialty?
   - Cardiologist
   - Lipidologist
   - Internist
   - Endocrinologist
   - Chemical Pathologist
   - Other healthcare professional

2. Do you manage patients with FH?
   - Yes
   - No

3. Which of the following best describes your clinical setting?
   - Government hospital
   - Private hospital
   - University Hospital
   - I do only research

4. In your clinical setting do you have access to genetic testing?
   - Yes

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### Post-Symposium Questionnaire

**About FH**

For each of the questions below, please select just ONE response that you think is most appropriate:

11. Which of the following holds true regarding familial hypercholesterolaemia (FH)?
   - Prevalence of FH varies between 1 in 200 to 1 in 500 worldwide.
   - FH tends to cluster within families.
   - Affected individuals can be either homozygotes or heterozygotes for the underlying mutation.
   - FH is a substantially under-diagnosed and under-treated condition.
   - All of the above.

12. The characteristic lipid abnormality in people with FH is:
   - Elevated LDL-C levels
   - Elevated LDL-C levels
   - Elevated lipoprotein (a) levels
   - Low HDL-C and elevated TG levels
   - Elevated triglycerides and low HDL-C levels

13. The most common mutation among people with FH involves the:
   - MBP 400 (familial hypercholesterolaemia)
   - CETP 300 (familial hypercholesterolaemia)
   - APOE 400 (familial hypercholesterolaemia)
   - PC 400 (familial hypercholesterolaemia)
Pre-Event Questionnaire
Pre-Event Questionnaire

Q1
Which most closely approximates to your specialty?

- Cardiologist: 8.6%
- Lipidologist: 45.7%
- Internist: 11.4%
- Diabetologist: 5.7%
- Chemical Pathologist: 4.3%
- Other healthcare professional: 24.3%

Q2
Do you manage patients with FH?

- Yes: 69.0%
- No: 31.0%
Q3
Which of the following best describes your clinical setting?

<table>
<thead>
<tr>
<th>Setting</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government hospital</td>
<td>16.9%</td>
</tr>
<tr>
<td>Private hospital</td>
<td>7.0%</td>
</tr>
<tr>
<td>University Hospital</td>
<td>53.5%</td>
</tr>
<tr>
<td>I do only research</td>
<td>22.5%</td>
</tr>
</tbody>
</table>

Q4
In your clinical setting do you have access to genetic testing?

- Yes: 61.4%
- No: 38.6%

Q5
In your clinical setting do you do cascade screening?

- Yes: 65.2%
- No: 34.8%
Q6
In which country do you currently live?
Post-Event Questionnaire
Q1
Which most closely approximates to your specialty?

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiologist</td>
<td>26.1%</td>
</tr>
<tr>
<td>Lipidologist</td>
<td>32.6%</td>
</tr>
<tr>
<td>Internist</td>
<td>15.2%</td>
</tr>
<tr>
<td>Diabetologist</td>
<td>0.0%</td>
</tr>
<tr>
<td>Chemical Pathologist</td>
<td>10.9%</td>
</tr>
<tr>
<td>Other healthcare professional</td>
<td>15.2%</td>
</tr>
</tbody>
</table>

Q2
Do you manage patients with FH?

- Yes: 71.1%
- No: 28.9%
Q3
Which of the following best describes your clinical setting?

<table>
<thead>
<tr>
<th>Setting</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government hospital</td>
<td>17.8%</td>
</tr>
<tr>
<td>Private hospital</td>
<td>4.4%</td>
</tr>
<tr>
<td>University Hospital</td>
<td>64.4%</td>
</tr>
<tr>
<td>I do only research</td>
<td>13.3%</td>
</tr>
</tbody>
</table>

Q4
In your clinical setting do you have access to genetic testing?

- Yes: 75.6%
- No: 24.4%

Q5
In your clinical setting do you do cascade screening?

- Yes: 67.4%
- No: 32.6%
Q6
In which country do you currently live?

- AR - Argentina
- AU - Australia
- CN - China
- CZ - Czech Republic
- DK - Denmark
- ES - Spain
- FR - France
- GB - United Kingdom
- GR - Greece
- HU - Hungary
- IE - Ireland
- IR - Iran
- IS - Iceland
- IT - Italy
- JP - Japan
- LV - Latvia
- NL - Netherlands
- NO - Norway
- PL - Poland
- PT - Portugal
- RU - Russia
- SA - Saudi Arabia
- SE - Sweden
- TW - Taiwan
- UZ - Uzbekistan
- ZA - South Africa
Pre- and Post- Event Questionnaire
Q7
How useful would a national FH registry be to your country?

Pre-event
- Very useful: 66.2%
- Somewhat: 32.4%
- Not at all: 1.5%

Post-event
- Very useful: 82.6%
- Somewhat: 15.2%
- Not at all: 2.2%
Q8
Do you feel that your FH patient’s LDL-C levels are optimally controlled?

Pre-event:
- Yes: 16.4%
- No: 83.6%

Post-event:
- Yes: 7.0%
- No: 93.0%

Q9
Do you feel that additional therapies are needed to optimise your care of FH patients?

Pre-event:
- Yes: 94.1%
- No: 5.9%

Post-event:
- Yes: 97.8%
- No: 2.2%
Q10
If genetic testing is not available, do you think it would help you manage your FH patients?

Pre-event: Yes 73.3%, No 26.7%
Post-event: Yes 81.6%, No 18.4%

Q11
Which of the following holds true regarding familial hypercholesterolaemia (FH)?

<table>
<thead>
<tr>
<th></th>
<th>Pre-event</th>
<th>Post-event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of FH</td>
<td>10.3%</td>
<td>2.4%</td>
</tr>
<tr>
<td>varies between 1 in</td>
<td>Prevalence of FH varies between 1 in 200 to 1 in 500 worldwide</td>
<td>Prevalence of FH varies between 1 in 200 to 1 in 500 worldwide</td>
</tr>
<tr>
<td>200 to 1 in 500</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>worldwide</td>
<td>FH tends to cluster within families</td>
<td>FH tends to cluster within families</td>
</tr>
<tr>
<td>FH tends to cluster</td>
<td>3.4%</td>
<td>0.0%</td>
</tr>
<tr>
<td>within families</td>
<td>Affected</td>
<td>8.6%</td>
</tr>
<tr>
<td>FH is a substantially</td>
<td>individuals can be either homozygotes or heterozygotes for the underlying mutation</td>
<td>FH is a substantially under-diagnosed and under-treated condition</td>
</tr>
<tr>
<td>under-diagnosed and</td>
<td>8.6%</td>
<td>0.0%</td>
</tr>
<tr>
<td>under-treated</td>
<td>All of the above</td>
<td>95.1%</td>
</tr>
<tr>
<td>condition</td>
<td>77.6%</td>
<td></td>
</tr>
</tbody>
</table>
Q12

The characteristic lipid abnormality in people with FH is ...

- Elevated LDL-C levels
- Elevated HDL-C levels
- Elevated triglyceride (TG) levels
- Low HDL-C and raised TG levels
- Elevated lipoprotein (a) [Lp(a)] levels

Q13

The most common mutation among people with FH involves the:

- HMG CoA reductase pathway
- LDL receptor pathway
- Apolipoprotein-B pathway
- PCSK9 pathway
- None of the above
Q14
The most significant health threat due to FH is from the development of:

- a. Tendon xanthomas
- b. Fulminant hepatic failure secondary to fatty infiltration of the liver
- c. Premature cerebrovascular disease
- d. Premature coronary artery disease
- e. Both (b) and (d)

Q15
Total cholesterol levels in people with untreated heterozygous FH typically range between:

- 3.5 – 7.0 mmol/L
- 8.0 – 15.0 mmol/L
- 18.0 – 22.0 mmol/L
- 0.8 – 1.8 mmol/L
- None of the above
Q16
According to the EAS guidelines, a target lipid goal of <2.5 mmol/L for FH is with regard to:

- Total cholesterol levels
- LDL-C levels
- HDL-C levels
- TG levels
- Lp(a) levels

Pre-event
91.1%
3.6%
1.8%
3.6%

Post-event
90.2%
9.8%

Q17
According to the EAS guidelines, which of the following is not true regarding lipid management goals in people with FH:

<table>
<thead>
<tr>
<th>Pre-event</th>
<th>Post-event</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.4% All subjects with FH must be offered intensive lifestyle modification</td>
<td>7.3%</td>
</tr>
<tr>
<td>8.9% Lipid-lowering treatment should be commenced immediately after FH diagnosis in adults, regardless of their symptoms</td>
<td>14.6%</td>
</tr>
<tr>
<td>10.7% Initiation of lipid-lowering treatment should be considered around the age of 8-10 years among children</td>
<td>4.9%</td>
</tr>
<tr>
<td>48.2% For adults with FH, statin therapy should be commenced at the lowest possible dose and then rapidly increased to the maximum tolerated daily dose</td>
<td>46.3%</td>
</tr>
<tr>
<td>26.8% None of the above</td>
<td>26.8%</td>
</tr>
</tbody>
</table>
Q18
Following treatment initiation, assessment of the efficacy and safety of lipid-lowering therapy is recommended (according to the EAS guidelines) in about:

Q19
The most cost-effective way of identifying undiagnosed FH cases is via: