



Press release 2 – Glasgow, March 22, 2015

## **83<sup>rd</sup> Annual Congress of the European Atherosclerosis Society (EAS) March 22-25, Glasgow, Scotland, UK**

### ***European Atherosclerosis Society Rises to the Challenge of the Underdiagnosis and Undertreatment of Familial Hypercholesterolaemia***

- **Launch of FH Studies Collaboration at EAS Congress in Glasgow**
- **Mission to change the lives of millions of people worldwide with inherited high cholesterol – familial hypercholesterolaemia (FH)**

The European Atherosclerosis Society announces the launch of the global EAS FH Studies Collaboration (FHSC), which aims to address gaps in FH care and education worldwide. The mission of the EAS FHSC is to empower the medical and global community to seek change in how FH is detected and managed, so as to promote early diagnosis and more effective treatment of this condition.

Lead of the FHSC initiative, **Professor Kausik Ray (Imperial College London, UK)**, said: *'This is a unique opportunity for us to change the lives of millions of people around the world by working as one and leave a lasting benefit for future generations. Through international collaboration with stakeholders we aim to generate large scale robust data on how FH is detected, managed and the clinical consequences of current practice on outcomes. We will work with all stakeholders including patient's organisations to ensure that state-of-the-art information is utilised to close gaps in knowledge and/or improve clinical practice for our FH patients.'*

Professor Ray leads an International Steering Committee comprising Dr Handrean Soran (UK); Professor John Kastelein, Professor G. Kees Hovingh (Netherlands); Professor Pedro Mata (Spain); Professor Gerald Watts (Australia); Professor Frederick Raal (South Africa); Professor Raul Santos (Brazil); and EAS President Professor Alberico L. Catapano (Italy).

Currently, more than 30 countries have already agreed to take part.

The FHSC will be officially launched at a European Board for Accreditation in Cardiology (EBAC) accredited Congress session on **Sunday 22 March at 10:00 am**.

#### **Why is this initiative critical?**

FH is one of the most common inherited conditions with new research showing that about one in 200 people have this condition.<sup>1</sup> If not detected and treated, FH causes premature heart disease due to the lifelong burden of high plasma levels of low-density lipoprotein

(LDL) cholesterol, or 'bad cholesterol'. However, if people with FH are detected early and treated with effective cholesterol-lowering therapy, they can have a normal life.

Yet, worldwide, less than 1 per cent of FH patients are diagnosed.<sup>1</sup> Even if patients are identified, most patients receive suboptimal treatment.<sup>2,3</sup>

### **How will the FHSC achieve its mission?**

The FHSC has two key objectives to address the gaps in FH care.

- First, to establish an international registry of observational studies on FH so as to gain in-depth understanding of the contemporary burden of both homozygous FH and heterozygous FH. Specifically this will investigate how patients are managed, treatments, barriers to care, long-term risks, impact of patient-specific and societal factors, gene-drug interactions and screening for FH.
- Second, to disseminate this information to an international audience of healthcare professionals, to improve awareness of the burden of FH, with the ultimate aims of developing a uniform, evidence-based standard of care, and at the same time, encouraging primary care physicians in particular to contribute actively to research.

### **What are the key events at EAS Glasgow?**

EAS Glasgow sees the launch of this important global initiative with two key events.

- At the official launch of the EAS FHSC on Sunday March 22, participants will discuss what can be learnt from the organisation of FH care in the UK, Asia Pacific Region and the Netherlands and how this can be translated locally. According to Professor Ray: *'Large scale global data are critical for influencing national and international policy on FH care.'*
- For the first time, the EAS is bringing together representatives of FH Patient Advocacy groups around the world, to learn from the successes and failures of patient advocacy in different countries, as well as how barriers to optimum FH care can be overcome.

According to **Dr Robert Cramb, Trustee of HEART UK, the Cholesterol Charity:**

*'HEART UK is pleased that the European Atherosclerosis Society is bringing together clinicians and patient advocacy groups to promote the awareness of familial hypercholesterolaemia (FH). HEART UK has consistently campaigned for the universal adoption of the National Institute for Health and Care Excellence NICE FH guideline CG71 in the UK. At present large areas of the UK are not offered the opportunity of the proper implementation of this NICE guideline with the adoption of cascade screening for FH with a subsequent identification of relatives and treatment programme initiated. The confluence of parties with interests in FH is a means of exchanging ideas of best practice and of influencing public health measures that can change outcomes in cardiovascular disease. We believe*

*that the interest of the EAS in bringing together these groups will enhance awareness of FH and influence practice. HEART UK hopes that this will in the long term lead to common committed strategies to screen appropriately for FH in Europe.'*

The EAS welcomes all stakeholders in FH care to this important event which aims to change the life of millions of people worldwide with FH.

### **More information**

For more information: <http://www.eas-society.org/fhsc.aspx> about events, surveys and progress.

Follow us on twitter #fhscglobalregistry

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### **Reference**

1. Nordestgaard BG, Chapman MJ, Humphries SE, et al; European Atherosclerosis Society Consensus Panel. Familial hypercholesterolaemia is underdiagnosed and undertreated in the general population: guidance for clinicians to prevent coronary heart disease: consensus statement of the European Atherosclerosis Society. *Eur Heart J* 2013;34:3478-90a. PUBMED link: <http://www.ncbi.nlm.nih.gov/pubmed/23956253>

This highly cited paper (free access) provides a state of the art review of the current status of FH care, with recommendations from the EAS Consensus Panel on diagnosis, management and treatment targets.

An accompanying paper focuses on homozygous FH.

Cuchel M, Bruckert E, Ginsberg HN, Raal FJ, Santos RD, Hegele RA, Kuivenhoven JA, Nordestgaard BG, Descamps OS, Steinhagen-Thiessen E, Tybjærg-Hansen A, Watts GF, Averna M, Boileau C, Borén J, Catapano AL, Defesche JC, Hovingh GK, Humphries SE, Kovanen PT, Masana L, Pajukanta P, Parhofer KG, Ray KK, Stalenhoef AF, Stroes E, Taskinen MR, Wiegman A, Wiklund O, Chapman MJ; European Atherosclerosis Society Consensus Panel on Familial Hypercholesterolaemia. Homozygous familial hypercholesterolaemia: new insights and guidance for clinicians to improve detection and clinical management. A position paper from the Consensus Panel on Familial Hypercholesterolaemia of the

European Atherosclerosis Society. Eur Heart J 2014;35:2146-57. PUBMED link:  
<http://www.ncbi.nlm.nih.gov/pubmed/25053660>

2. Pijlman AH, Huijgen R, Verhagen S et al. Evaluation of cholesterol lowering treatment of patients with familial hypercholesterolaemia: a large cross-sectional study in the Netherlands. Atherosclerosis 2010;209:189-94.  
<http://www.ncbi.nlm.nih.gov/pubmed/19818960>

3. Béliard S, Carreau V, Carrié A, Giral P, Duchêne E, Farnier M, Ferrières J, Fredenrich A, Krempf M, Luc G, Moulin P, Bruckert E. Improvement in LDL-cholesterol levels of patients with familial hypercholesterolemia: can we do better? Analysis of results obtained during the past two decades in 1669 French subjects. Atherosclerosis 2014;234:136-41.  
<http://www.ncbi.nlm.nih.gov/pubmed/24637413>

**For more information on FH, refer to:**

Heart UK, The Cholesterol Charity: <http://heartuk.org.uk/>

National Institute for Health and Care Excellence: Identification and management of familial hypercholesterolaemia. NICE guidelines CG71 (August 2008).  
<https://www.nice.org.uk/guidance/cg71>

The FH Foundation: <http://thefhfoundation.org/>

Joint ESC/EAS Guidelines: Catapano AL, Reiner Z, De Backer G, Graham I, Taskinen MR, Wiklund O, Agewall S, Alegria E, Chapman M, Durrington P, Erdine S, Halcox J, Hobbs R, Kjekshus J, Filardi PP, Riccardi G, Storey RF, Wood D; European Society of Cardiology (ESC); European Atherosclerosis Society (EAS). ESC/EAS Guidelines for the management of dyslipidaemias. The Task Force for the management of dyslipidaemias of the European Society of Cardiology (ESC) and the European Atherosclerosis Society (EAS). Atherosclerosis 2011;217:3-46. PUBMED Link: <http://www.ncbi.nlm.nih.gov/pubmed/21882396>

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