FH EUROPE

12th Lipid Club and Therapeutic Apheresis 2017 Jules Payne, FH EuropeTrustee

FH Europe is supported by an educational grant from Amgen Limited. We have also received support from Aegerion Pharmaceuticals, Inc and Akcea Therapeutics Inc. Further support is sought from both Industry & Public Funds.



FH Patient Organizations and Advocacy Groups together

- Idea born in London Feb 2015 between HEART UK, FH Sweden, FH Portugal, FH Norway and FHchol Austria.
- More than 20 FH patient organisations speaking in one voice





Governance of FH Europe

- Established as a legal entity on Dec. 13, 2016
- Charitable incorporated organization (CIO)
- Five Trustees, currently
 - Jules Payne (Chair)
 - Gunnar Karlsson (Treasurer)
 - Gabriele Hanauer-Mader
 - Athanasios Pallidis
 - Isabel Gaspar
- Voluntary role
- Trustees serve different terms of office
- Meet four-six times per year
- Each country is independent of the network





What we are about

Awareness raising



Share/learn from each other

Empowering FH Patient Advocates

Lobby for change

Co-operate medical / science world









Diana Maxwell



Bi-monthly e-flash



Twitter account



Website holding page



Lobbying material development



HCP conferences (ECIM & EAS)



Directory production

Registered Charity no. 1170731



2016 Activities

Network meeting – London (Nov)



Planned Activities 2017



Increase presence



Develop full website



24 Sept awareness day

Share member news



Network meeting Budapest (Nov)



Advocacy training & toolkit



Local lobbying



Call to Action – 2017 priorities



FH Europe is supported by an educational grant from Amgen Limited

> Registered charity no.1170731 Charity registered in England and Wales

Call to Action on

Familial Hypercholesterolaemia (FH) & Cardiovascular Diseases



FH is estimated to affect at least one million people across the European Union, but in many countries only a limited number of cases are actually diagnosed (less than 1% in some countries).



The lack of diagnosis is a barrier for the effective prevention of premature coronary artery disease and impacts the quality of life and economic and social contributions of individuals and families with FH.

We therefore call for the following actions to be supported by the European Parliament, the European Commission, the European Council and all concerned stakeholders.





























CALL ON THE EUROPEAN COMMISSION TO:

- 1. Work towards the development of an EU strategy dedicated to prevention of cardiovascular diseases in high risk patients, including a chapter on FH and early identification of FH high-risk individuals;
- 2. Encourage the EU, through the European Health Programme 2014-2020, to reduce chronic diseases and in particularto make stronger efforts to fully integrate non-rare genetic diseases such as Fit: discuss with the EU policy-makers the inclusion of funding dedicated to identifying prevention measures to capture high-risk populations, as well as how these measures can be integrated in healthcare settings;
- 3. Encourage the EU, through the European Health Programme 2014-2020, to fund projects aiming at mapping existing early diagnosis and screening for FH.

CALL ON THE EUROPEAN PARLIAMENT AND ITS MEMBERS TO:

- 1. Support the development of an EU strategy dedicated to prevention of cardiovascular diseases for high risk patients, including a chapter on FH and early identification of FH high-risk individuals:
- 2. Encourage and facilitate the exchange of best practices in managing and caring for FH patients with particular attention to care pathways;
- 3. Consider the possibility of issuing a new European Parliament Resolution on action to tackle cardiovascular disease

CALL ON THE MEMBER STATES TO:

- 1. Work together with the European Commission towards the development and implementation of a European strategy dedicated to prevention of cardiovascular diseases for high risk patients including FH: discuss with policy-makers how to develop, adopt, and/or improve and implement public health strategies that effectively address prevention of cardiovascular diseases in highrisk patients, including FH patients;
- Exchange national best practices regarding the establishment of patient registries, which can contribute to more effective diagnosis of FH, particularly within families: discuss with policy-makers how to implement effective means to exchange best practices.
- 3. Raise awareness at national and regional/local level on the causes, risk-factors and consequences of FH among healthcare practitioners at all levels, with special attention to primary care settings.

CALL ON ALL THE STAKEHOLDERS TO:

- 1. Ask policy-makers at all levels, to develop, adopt, and/ or improve and implement public health strategies that effectively address prevention of diseases cardiovascular in high risk patients, including FH patients;
- 2. Establish an EU-wide network to share data, best practices, evidence on screening and management of



CTA published 2015: 2017 priorities in bold



















FH Heat Map of Europe



Our Take-Home-Message



We are working together to provide a stronger future for individuals and families with FH.









What we are about

Vision

 No premature deaths or suffering caused by cholesterol and/or cardiovascular disease.

Mission

 For UK adults to know and understand their cholesterol levels and take appropriate action.

How?

Providing expert support, education & influence.



Communications



>2m hits per year





>200,000 impressions per month



Consistent PR coverage





FH Intelligence Network



Services





HCP online/off-line education

Visuria LearningConn



Patient meetings

Cholesterol Helpline





Children & young people programme

Ambassador programme

FH Europe

Cholesterol - A problem solved?



31st Annual Medical & Scientific Conference

Wednesday 5 - Friday 7 July 2017

Warwick Arts Centre, University of Warwick, Coventry, UK



Key Deadlines:

Abstract submissions: Friday 10 March

Travel grant applications: Friday 7 April

Early bird registrations: Monday 8 May



heartuk.org.uk/conference

Influencing key opinion leaders

Atherosclerusis 255 (2016) 128-139



EAS Updates

HEART UK statement on the management of homozygous familial hypercholesterolaemia in the United Kingdom



Michael France ^{a,*}, Alan Rees ^b, Dev Datta ^c, Gilbert Thompson ^d, Nigel Capps ^e, Gordon Ferns ^f, Uma Ramaswami ^g, Mary Seed ^h, Dermot Neely ⁱ, Robert Cramb ^j, Carol Shoulders ^k, Mahmoud Barbir ¹, Alison Pottle ^m, Ruth Eatough ⁿ, Steven Martin ^o, Graham Bayly ^p, Bill Simpson ^q, Julian Halcox ^r, Ray Edwards ^b, Linda Main ^s, Jules Payne ^b, Handrean Soran ^{t, u}, for HEART UK Medical Scientific and Research Committee

- Cholesterol into the NHS 5 year forward view
- National Screening Committee, upward cascade testing
- Death certificates
- FH Registry PASS licences and Governance group



Thank you for your for listening.

