

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 particular to make stronger efforts to fully integrate non-rare genetic diseases such as FH: 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 high-risk patients, including FH patients;**
2. **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 cardiovascular diseases in high risk patients, including FH patients;
2. Establish an EU-wide network to share data, best practices, evidence on screening and management of heart disease.



CTA published 2015;
2017 priorities in bold