Cardiomyopathies Matter

EU cardiovascular disease policies must TACKLE CARDIOMYOPATHIES

Cardiovascular diseases (CVDs) are the leading cause of death and cost €282 billion annually across the EU.[1] Cardiomyopathies (CMs) – a group of diseases affecting the heart muscle – affect around 1.5 million people in the EU, UK and Norway. They can increase the risk of sudden cardiac death, cause incapacitating symptoms, impair quality of life, and are a leading reason for heart transplantation. Major forms of CMs are often inherited.[2,3]

Policy recommendations for the 2024-2029 EU mandate

An EU Cardiovascular Health Action Plan should be implemented, addressing cardiomyopathies and other inherited CVDs. It should include measures to:

1 Promote early diagnosis

- Support Member States in early CM detection through a life-course European Cardiovascular Health Check[4]
- Promote screening of family members of patients diagnosed with inherited CMs, including genetic counselling and testing where recommended[5]
- Recognise the importance of early detection in the upcoming discussions on preventive health and NCDs

2 Empower patients and families

- Promote self-care and shared decision-making e.g. via education/health literacy, improved patient-doctor communication, and digital health tools
- Ensure patients do not face stigma or discrimination following a positive genetic test (e.g. in employment, education, or finance)
- Promote access to holistic support services, including psychological and mental health services, as part of the EU comprehensive approach to mental health
- Promote the roles of patient organisations in education, support, and decision-making

3 Promote access to expert care

- Facilitate cross-border access to specialist care
- Share best practices on efficient referral pathways, organisation models, workforce resourcing, digital infrastructures, and access to genetic counselling and testing
- Support implementation/adherence of/to CVD care guidelines
- Recognise the importance of specialist nurse for inherited CVDs as part of the upcoming discussions on healthcare workforce

4 Support research

- Support patient registries and harmonisation and utilisation of real-world data via the EHDS
- Implement data-sharing policies that facilitate research

5 Raise public awareness

- Build awareness about inherited CVDs
- Support public training in cardiopulmonary resuscitation (CPR) and use of automated external defibrillators

ERN GUARD-Heart
Gateway to Uncommon And Rare Diseases of the Heart

ERN GUARD-Heart

The GUARD-Heart European Reference Network (ERN) facilitates diagnosis and care for rare and complex heart diseases across Europe. We welcome efforts of the EU, through the JARDIN joint action, to integrate ERNs into National healthcare systems. We now encourage national and regional health authorities to take this joint action forward to fully achieve a more integrated European Health Union for rare and complex CVDs.

The **Cardiomyopathies Matter Roadmap** provides EU and national policy recommendations to help improve diagnosis, care, and support for patients and families.[2,3]

Download the roadmap here

"The Current Council Conclusions on Cardiovascular health show the EU's momentum in this area, but more is needed. Through an EU Cardiovascular Health Action Plan, national and regional health systems across the EU will be better placed to tackle the negative impact of cardiomyopathies and other inherited conditions, promote early diagnosis, and harmonize high-quality care for all patients in Europe"

Prof. Iacopo Olivotto, Italy

"We need actions at the EU and national levels that promote public training in cardiopulmonary resuscitation and the use of defibrillators as well as greater access to psychological support and genetic testing"

Ester Costafreda, SAMS, Spain

Disclaimer:

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References:

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