

Improving cardiomyopathy detection and care in Belgium

Raise Awareness of Cardiomyopathies Matter

Cardiomyopathies Matter is a multi-stakeholder initiative that aims to raise awareness about cardiomyopathies and to ensure they receive the policy attention they warrant from healthcare system decision-makers and influencers at the EU and national levels.

~1 in 500¹
adults in the general population are affected by cardiomyopathies

The tip of the iceberg

Gaps in recommended investigations to confirm diagnosis

Undiagnosed, misdiagnosed and late diagnosed cases

Lack of knowledge, awareness and education among healthcare professionals

Insufficient family screening

Why it matters?

Cardiomyopathies are a group of cardiovascular diseases (CVDs) affecting the heart muscle. They reduce the ability of the heart to pump blood and are often caused by inherited pathogenic genetic variants.

Cardiomyopathies pose a major burden for patients, families and healthcare systems, yet they receive little policy attention.

Considerable challenges exist throughout the patient care pathway.

A substantial impact on patients and families



The main symptoms relate to:

Heart Failure

- fatigue, chest pain, breathlessness
- reduced exercise capacity
- increased risk of death

Abnormal heart rhythms

- palpitations
- light-headedness, fainting
- increased risk of stroke and sudden cardiac death

Reduced well-being and quality of life:



anxiety and depression



difficulties in obtaining life insurance or mortgage



out-of-pocket expenses



limitations in employment, education, daily activities

A societal burden

CVD cost **€210 billion/year²** across the EU



In France,³ cardiomyopathies are responsible for:

- 51%** of all heart transplants
- 33%** of defibrillator implantations
- 38%** of mechanical circulatory supports
- 11%** of hospitalisations for heart failure



In Germany,⁴ cardiomyopathies account for:

- 65%** of all heart transplants
- 70%** of all heart transplants in children under 15 years



What about Belgium? Currently no coordinated effort to collect data on cardiomyopathies in Belgium.

Policy recommendations

Policy actions are necessary to address key challenges and unmet needs throughout the care pathway for cardiomyopathies.



We call on **Belgian federal and regional decision-makers to implement** the following recommendations within **Cardiovascular Health plans**, and existing policies and initiatives.

A strong ecosystem for R&D, innovation and clinical trials

- Support R&D in the field of cardiomyopathies
- Encourage the development of precision medicines

Patient support: holistic approach

- Multidisciplinary approach
- Promote patient organisations
- Include PREMs and PROMs in healthcare policy

Screening, early detection and prevention

- Family screening
- Public awareness
- Cardiovascular health checks
- Genetic testing after cardiac arrest/sudden cardiac death
- Professional education and decision-support tools for HCPs to facilitate diagnostic precision and ensure timely referrals
- Develop a framework to inform families about the diagnosis of cardiomyopathies

Data collection and data sharing

Facilitate evidence-based policy through:

- Data collection specifically on cardiomyopathies
- Cardiomyopathies Registry including information about MRI results, genetic testing...
- Framework for molecular autopsy and post-mortem analyses

Raising awareness, social inequality and access to specialist care

- Prioritize accessible, affordable and qualitative care
- Raise awareness of cardiomyopathies among HCPs that do not specialize in cardiovascular health and in the general public
- Empower people to recognize symptoms

Lifestyle

- Encourage healthier lifestyle choices

Future policy actions

A dedicated Cardiovascular Health Action Plan and a Cardiovascular Health Mission giving specific attention to cardiomyopathies should be implemented at the Belgian level in cooperation with the Regions and relevant stakeholders. The ultimate goal of this Interfederal strategy is to ensure early diagnosis and qualitative care for patients with cardiomyopathies in Belgium.

www.cardiomyopathiesmatter.org

Cardiomyopathies Matter is funded by Bristol Myers Squibb. Nothing contained herein is intended, nor should be interpreted, to promote Bristol Myers Squibb nor any BMS product or agent.

1. Maron, B. J., et al. (2003). American College of Cardiology/European Society of Cardiology Clinical Expert Consensus Document on Hypertrophic Cardiomyopathy: a report of the American College of Cardiology Foundation Task Force on Clinical Expert Consensus Documents and the European Society of Cardiology Committee Castelletti S, et al. Indications and utility of cardiac genetic testing in athletes. *Eur J Prev Cardiol* 2022;29:1582-91

2. European Heart Network. European cardiovascular disease statistics. 2017 <https://ehnnheart.org/cvd-statistics/cvd-statistics-2017>

3. Lannou S, et al. The public health burden of cardiomyopathies: insights from a nationwide inpatient study. *J Clin Med* 2020;9:92

4. Deutschen Stiftung für Organtransplantation. Organ Donation and Transplantation in Germany 2021 [in German]. <https://dso.de/organspende/statistiken-berichte/jahresbericht>