

# Cardiomyopathies Matter

Tackling under-recognized cardiovascular diseases in Europe

## Launch event report

Tuesday 15th of November 2022, 15:00-17:00  
European Parliament

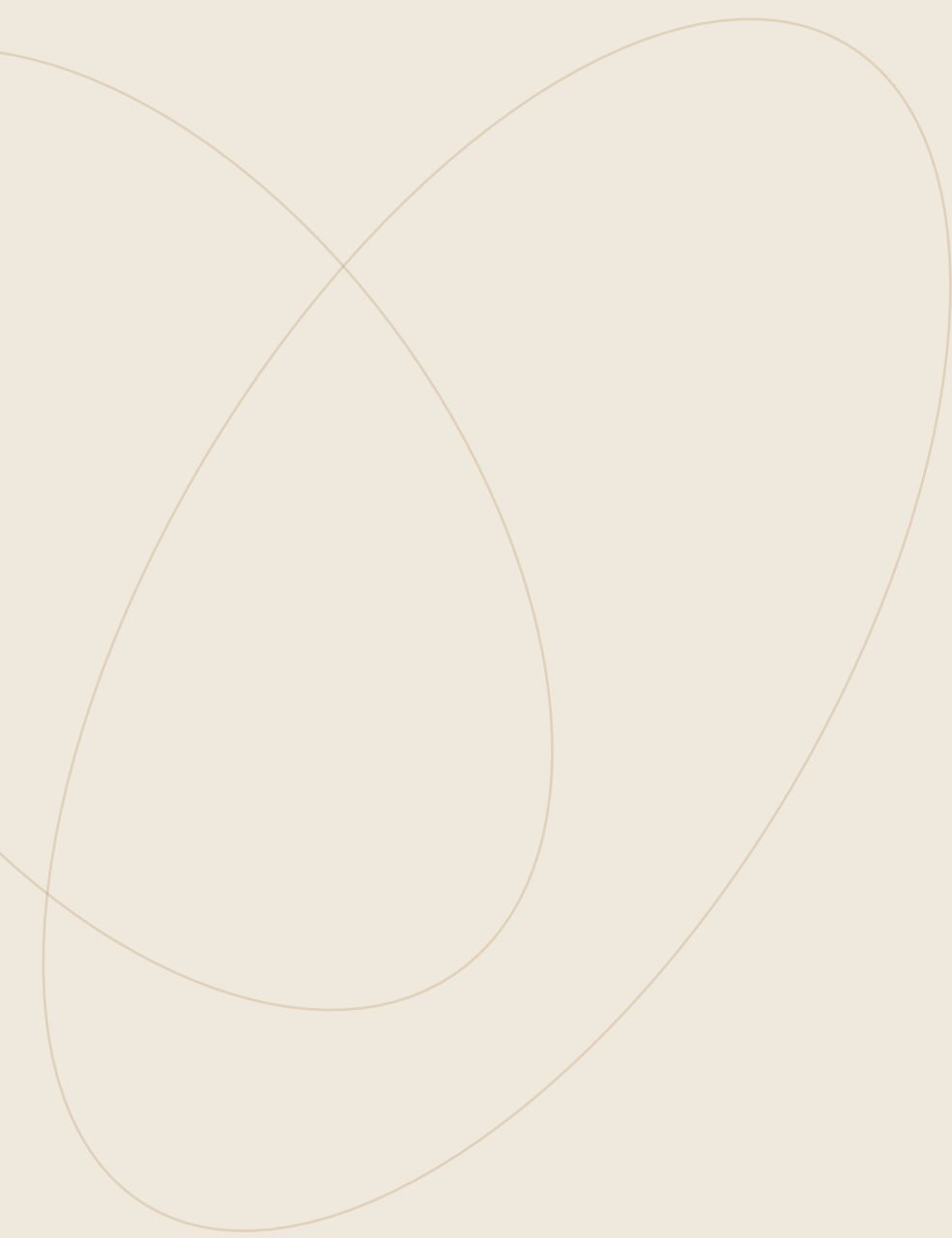


Cardiomyopathies  
Matter

**The Cardiomyopathies Matter initiative, and its Policy Roadmap “Cardiomyopathies Matter – a Policy Roadmap to improve cardiomyopathy detection and care in Europe” were launched at a hybrid (in person- and online) event at the European Parliament (EP).**

**The Roadmap is a unique and comprehensive report providing policy solutions at European Union (EU) and national level to the unmet needs and challenges faced by cardiomyopathy patients. It includes key recommendations on how to leverage EU initiatives to improve early diagnosis, disease management, patient empowerment and foster research and innovation, whilst calling for a more comprehensive approach to cardiovascular disease (CVD) through dedicated EU-level and national Cardiovascular Health Action Plans.**

**The launch event brought together European policymakers, patient representatives, health-care professionals, industry representatives, and other interested stakeholder groups.**



## Opening

Tamsin Rose, as moderator, opened the event and greeted Members of the European Parliament (MEP) Dr Jouzas Olekas, Mr Brando Benifei and Prof. Maria da Graça Carvalho, who all made welcoming remarks.

MEP Dr Olekas, host of the event and member of the MEP Heart Group, emphasized the importance of shining light not only on the burden of CVDs in Europe, but also on the contribution of less common CVDs such as cardiomyopathies to this burden. He mentioned cooperation and joined-up thinking as two key measures to improve cardiomyopathy diagnosis and care in Europe.

MEP Prof. Carvalho, co-chair of the MEP Heart Group, highlighted that the patient-centred approach of the Roadmap gives it an added value. She described the Roadmap as a great blueprint and called on her colleagues in the European Parliament and the European Commission, and in countries, to read its recommendations and to translate these into concrete policy change for patients.

In a video message, MEP Benifei, co-chair of the MEP Heart Group welcomed the Commission's recent efforts to tackle CVD (e.g. via the Healthier Together initiative) but pointed out that more remains to be done to bring about transformational changes for European cardiomyopathy patients. He emphasised that early diagnosis is crucial to ensure patients receive timely treatment and lifestyle advice.



## Patient testimonial - Open Hearted: A life with cardiomyopathy

Patricia Vlasman, from Cardiomyopathie Onderzoek Nederland (Foundation Cardiomyopathy Research The Netherlands), shared her experience as a cardiomyopathy patient and patient advocate. After her mother suddenly collapsed and a DNA test was carried out, Ms. Vlasman was diagnosed with hypertrophic cardiomyopathy at the age of 13. In 2018, she received a heart transplant. She described the days in which her illness prevented her from working, getting life insurance or buying a house as the darkest days of her life, and thanked her donor for allowing her to live a "second life" through his/her heart.

She explained how worrying it is, knowing that cardiomyopathy could end your life at any time. As such, Ms. Vlasman called for more investment in EU-driven research and data infrastructures, to not only gain more insight into the number of people with an inherited form of cardiomyopathy but to also achieve appropriate cardiomyopathy care.



**"Cardiomyopathy is a silent killer that can strike out of nowhere. Cardiomyopathy is also a chronic disease that holds people hostage to a life that is shrinking due to cardiac arrhythmias and hospitalizations."**

*Patricia Vlasman, Cardiomyopathie Onderzoek Nederland*

# The underestimated burden of Cardiomyopathies in Europe: Time to Act Now!

Prof. Stefan Janssens, head of the Cardiovascular Disease Department at the University Hospitals (UZ) Leuven, Belgium, explained that cardiomyopathies are estimated to affect around 1 in every 330 people in the EU. However, he stressed that this figure under-estimates the prevalence because many patients are diagnosed late, or are even not diagnosed at all, owing to a lack of proper screening, the non-specific nature of the symptoms, or the insufficient awareness of these diseases by healthcare professionals, among other reasons. Importantly, the symptoms experienced by patients (e.g. fatigue, breathlessness, palpitations, risk of sudden cardiac death) greatly reduce their wellbeing and quality of life (QoL), and can worsen over time.

Prof. Janssens reported that cardiomyopathies make an important contribution to the healthcare spending of CVDs (which cost around €210.8 billion/year across the EU) – primarily through hospitalizations due to complications such as heart failure.

He also cited the productivity losses from death and illness among working age patients and the costs that carers forgo to provide informal, unpaid care to patients as important indirect socioeconomic costs.



# Presentation of the Cardiomyopathies Matter Policy Roadmap

Prof. Iacopo Olivetto, head of the Cardiomyopathy Unit in the Department of Experimental and Clinical Medicine at the University of Florence, presented the Cardiomyopathies Matter Roadmap itself. For the first time, this report gives insight into the key challenges and unmet needs of cardiomyopathy patients, and outlines the need to raise awareness about this group of diseases to ensure they receive the policy attention they warrant from healthcare systems decision-makers and influencers at EU and national level.

It presents recommendations necessary to address key challenges and unmet needs throughout the care pathway for cardiomyopathies – spanning diagnosis, disease management, holistic support, patient empowerment and research and innovation – to be implemented within or in association with EU and national Cardiovascular Health Action Plans.



The report and summary infographic are available on the [Cardiomyopathies Matter website](#)

# Panel discussion - Policy solutions to the unmet needs and challenges in cardiomyopathies: The Way Forward

The panel discussion focused on exploring the different policy solutions that could be delivered to meet some of the unmet needs and challenges in cardiomyopathies.

Prof. Hugo Katus, head of Internal Medicine at the University of Heidelberg, Germany, and chair of the European Society of Cardiology (ESC) Innovation Think Tank, affirmed that dedicated EU and national Cardiovascular Health Action Plans should be implemented – since CVDs are the most frequent cause of death and contribute to a substantial loss in the quality of life of many Europeans. These plans should adopt a holistic approach tackling deficiencies throughout the care pathway, from patient empowerment and psychological care to research and innovation. Likewise, Prof. Katus acknowledged that the upcoming regulation on the European Health Data Space (EHDS) will also greatly benefit CVD patients, especially those with rare inherited conditions such as cardiomyopathies. In this sense, the EDHS may trigger a harmonization of the available health data, leading to the standardization of the diagnostic and therapeutic pathways across Europe and the development of high-quality registries.

Cross-border interaction and exchange of data would contribute to empowering patients and providing them with a personalized and individualized treatment better adapted to their needs.

MEP Dr Olekas noted that the MEP Heart Group, and the European Parliament as a whole, have a role to play in ensuring that cardiovascular health becomes a priority at European level and that the EU Cardiovascular Health Action Plan becomes a reality. The EP can contribute by calling on the Commission to act, prepare a Cardiovascular Health Action Plan and ensure its implementation; by organizing events, such as the Cardiomyopathies Matter launch event, to raise awareness; and by cooperating with patient organizations and the different stakeholders involved. In addition, Dr Olekas referred to cooperation and continuous dialogue with Member States, the involvement of patients in the process and the creation of strong networks between the different stakeholders as ways to ensure that the European plans and initiatives that could benefit cardiomyopathy patients (e.g. the non-binding EU Healthier Together initiative) are implemented effectively at a national level.



**“In the European Union, all patients should have the same opportunities despite where their live, their wealth or their gender”**

*MEP Dr Jouzas Olekas, European Parliament*

Dr Ruth Biller, chair and co-founder of ARVC-Selbsthilfe e.V. (Germany) and chair of the European Patient Advocacy Group of the ERN GUARD-Heart, stressed that European Reference Networks (ERNs) have been instrumental in connecting rare disease communities and supporting patients across Europe. Dr Biller explained that the ERN GUARD-Heart has been successful in raising awareness and enabling early diagnosis of cardiomyopathies and other rare diseases through educational videos for healthcare professionals; webinar series with case discussion; the setting up of clinical patient management

systems (CPMS) where experts try to solve unexplained cases; the publication of disease-specific brochures for patients; and financial contribution for patients meetings. However, there is still room for improvement, said Dr Biller. To exploit the ERNs’ full potential, they need to be integrated into the national healthcare systems, financial support for registries should be improved and patient representatives should be more involved at all levels to bring their perspective into research, guideline development, congresses, etc.



**“Nobody knows about the European Reference Networks, except for those who are already involved, so we need to raise awareness”**

*Dr Ruth Biller, chair and co-founder of ARVC-Selbsthilfe e.V.*

Dr Biller also highlighted the importance of supporting cardiomyopathy patients' and their families' mental health and well-being, stressing the need to adopt a holistic assessment of the disease impact. Patients should be able to access relevant supportive care, including psychological support, to address their worries (including the risk sudden cardiac death) and feelings of guilt (for example with respect to disease inheritance).

Therefore, psychological interventions should be reimbursed and waiting times for psychotherapy should be reduced. Moreover, the use of patient reported outcome measures (PROMs) to assess patients' QoL should be promoted and the patient organizations' mission to provide information and resources to patients and families should be supported.



**“Doctors are the experts on cardiomyopathy, but patients and their families are the experts on living with cardiomyopathy.”**

*Dr Ruth Biller, chair and co-founder of ARVC-Selbsthilfe e.V.*

At the national level, the Spanish Centers, Services and Units of Reference (CSURs) are considered a best practice example of expert centre networks. As explained by Enrique Terol García, Health Attaché at the Permanent Representation of Spain to the EU, even though Spain is a decentralized state in which healthcare competences are transferred to the 17 Autonomous Communities, all Spanish cardiomyopathy patients can be referred to one of the nine CSURs dealing with these diseases. These centres provide a multidisciplinary team care, bringing benefits of equity in access and earlier diagnosis. Mr Terol also highlighted the importance of the ERNs and called for more political support and for a full integration of the CSURs in the ERN system.

According to Matteo Pincirolì, Chairman of the Global Heart Hub (GHH) Cardiomyopathy Patient Council, the ultimate benefit for patients and the real leverage and implementation of EU initiatives at national level will come when local patient organizations are involved in all stages of the legislative process. Mr Pincirolì cited the European Patients' Academy on Therapeutic Innovation (EUPATI) as an example of a multistakeholder private-public partnership that empowers patients by giving them enough basis to manage the broader spectrum of their disease (e.g. training patients on technical medical vocabulary or on how clinical trials work) and by engaging with the different stakeholders locally.

Moreover, Mr Terol referred to the EHDS as a great opportunity for cardiomyopathy patients and mentioned that the upcoming Spanish presidency of the Council of the EU (July-December 2023) will devote all efforts to reach an agreement in the Council to approve this piece of legislation. Mr Terol noted the importance of ensuring interoperability and the exchange of data to improve the quality of care and develop new research opportunities and treatments that ultimately benefit patients.

Furthermore, he referred to the six guiding principles for patient involvement and engagement in cardiomyopathy research developed by GHH as key elements that will lead to better outcomes for people affected by this condition. These are inclusivity and empowerment, accountability, transparency, collaboration, communication, and impact. Mr Pincirolì also referred to equity of access and equity of treatment around different diseases as the ideal end point of the EU initiatives and the upcoming pieces of legislation.



**“We can't make patients the end users of something that has been thought through by someone else, but rather active players of the process”**

*Matteo Pincirolì, Chairman of the Global Heart Hub*

## Q&A

The panel discussion was followed by a Q&A session involving onsite and online participants.

When answering a question about the feasibility of broad population screening, Prof. Olivotto warned about the consequences of screening without sufficient expertise. As cardiomyopathies are difficult to diagnose, by doing broad population screening, we run the risk of over diagnosing healthy young people. Before promoting general population screening, widespread cardiomyopathy expertise among physicians should be developed. Prof. Olivotto hoped that with the growing research on cardiomyopathies, this group of conditions might stop being unknown and instead becomes fully understood.

Prof. Antoine Bondue, President of the Belgian Heart League and member of the ESC Council on Cardiovascular Genomics, highlighted the importance of raising awareness of screening among families who have a relative that has been diagnosed with a cardiomyopathy. Prof. Bondue stressed the significance of providing patients and their family with expert genetic counselling.

Dr Biller also insisted on the importance of raising awareness about the reality of cardiomyopathies and of genetic testing after cardiac arrest to promote early diagnosis. She argued that many people have never heard of cardiomyopathies, and not all general practice doctors and cardiologists are experienced in diagnosing them. This, together with the unspecific symptoms suffered by patients, means that many people go undiagnosed.

Mr Pinciroli referred to the two different “layers” of referral to a specialist: the general practice doctor needs to refer the patient to a cardiologist – who should be specialized in cardiomyopathies. Prof. Olivotto agreed – the key point is having a good network to refer the patient to once there is a suspicion.



**“We should stop seeing cardiovascular disease (only) as atherosclerotic disease. There is a full spectrum of cardiomyopathies that are highly relevant for our daily practice”**

*Prof. Bondue, President of the Belgian Heart League*

## CLOSING

Dr Jouzas Olekas closed the meeting by thanking the participants, especially patient representatives Ms Vlasman, Ms Biller and Mr Pinciroli whose contribution he described as “essential when developing policies”. Dr Olekas insisted on the importance of going further with an integrated Cardiovascular Health Plan that would encompass inherited cardiac conditions. He alluded to cooperation with Member States in putting this important measure on the EU agenda and guaranteeing successful implementation at national level as crucial.



**“Together we can contribute to shaping holistic policies that take into consideration the whole span of cardiovascular diseases. We now have a compelling document with the Cardiomyopathies Matter Roadmap to guide us through this process”**

*MEP Dr Olekas, European Parliament*

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