Cardiomyopathies Matter

SUMMIT2024

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Building political momentum for cardiomyopathies

Summit Report

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The Cardiomyopathies Matter (CMatter) Summit 2024 – 'Building political momentum for cardiomyopathies' took place in a hybrid format (in person and online) at Town Hall Europe on 12th November 2024. The Summit aimed to remind EU and national policymakers of the substantial burden posed by cardiomyopathies and other inherited cardiac conditions, present a set of policy recommendations to tackle this group of diseases, and showcase the success stories emanating from the various CMatter's national chapters.

In addition to the EU initiative, there are several national chapters of Cardiomyopathies Matter across European Countries: Spain, Italy, Belgium, Romania, The Netherlands, Poland and Hungary.

During the Summit, Cardiomyopathies Matter reminded participants of its 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 Cardiomyopathies Matter Summit 2024 brought together European policymakers, patient representatives, healthcare professionals, and other stakeholder groups.

PATIENT TESTIMONIAL – FOSTERING COLLABORATION TO OVERCOME THE CONSEQUENCES OF CARDIOMYOPATHY FOR FAMILIES

Ester Costafreda, the co-founder of the Spanish organisation for arrhythmias associated with sudden death (SAMS), opened the Summit by sharing her experience as a family member of people who passed away due to an inherited cardiac condition. Following the death of her 15-year-old son in 2014, her family discovered through genetic testing during the autopsy that he suffered a cardiomyopathy. As a result of this finding, Ester's family also discovered that her father had also died due to a cardiomyopathy in 1975. Ms Costafreda explained that cardiomyopathies can drastically change someone's life and that they are invisible diseases difficult to understand, even by healthcare professionals.

Due to her own experience, she found the determination to create a patient advocacy group that provides a community for patients. SAMS has three overarching goals: raising awareness about inherited cardiac conditions, providing psychological support to patients and families due to the heavy mental health burden that cardiomyopathies pose on them, and provide training programmes on cardiopulmonary resuscitation and how to use defibrillators.

"Imagine a future where no parent or sibling has to face the heartbreak of sudden death due to a cardiomyopathy... We, and the policymakers we elect, have the power to save these lives."

Ester Costafreda

A STATE OF PLAY OF CARDIOMYOPATHY POLICIES ACROSS EUROPE

Prof. Iacopo Olivotto, Chief of Cardiology in the Department of Experimental and Clinical Medicine at the University of Florence and at the Meyer University Children Hospital, Florence, Italy, explained the general commonalities around this group of disease and emphasized that cardiomyopathies are a major cause of heart failure: one-fourth of heart failure patients usually suffer from cardiomyopathy. However, unlike other cardiovascular diseases, little has been spent to tackle these conditions. He also noted that cardiomyopathies are often misdiagnosed. Against this backdrop, Prof. Olivotto informed that effective treatments do exist but access varies across Europe.

Moving into the presentation of the article "Family matters: health policies to tackle cardiomyopathies across Europe", an article written by the CMatter Steering Group and which has recently been accepted for publication in the European Heart Journal, Prof. Olivotto devoted time to presenting a summary table of the state of play of cardiomyopathy care in European countries. The key findings are that very few countries have specific plans devoted to cardiomyopathies, genetic testing is underutilized, and the allocation of research resources is unsatisfactory.

"Cardiomyopathies have been systematically ignored for many years. Now we know how many people they affect, and how impactful they are, we must act."

Prof. Iacopo Olivotto

CMATTER'S RECOMMENDATIONS FOR THE NEW MANDATE

Prof. Jean-Noël Trochu, Head of Thorax and Nervous System Institute and Heart Failure and Cardiomyopathies unit at the Nantes University Hospital, France, presented the policy recommendations that the Cardiomyopathies Matter initiative has been advocating since its foundation.

These recommendations seek to address key challenges and unmet needs throughout the care pathway for cardiomyopathies – spanning from early diagnosis including through genetic testing or magnetic resonance imaging (MRI), disease management through access to expert care, holistic support, patient empowerment, growing public awareness about the conditions, and research and innovation.

In his presentation, Prof. Trochu also stressed that cardiovascular diseases are the leading cause of death in Europe. Consequently, he urged for EU cardiovascular disease action that tackles cardiomyopathies, a condition that affects roughly 1.5 million patients in Europe.

The Cardiomyopathies Matter Roadmap with its policy recommendations is available on the Cardiomyopathies Matter website.

PANEL DISCUSSION 1 – PUTTING CARDIOVASCULAR DISEASES UNDER THE SPOTLIGHT

The first panel discussion of the Summit focused on how the current EU policy landscape can help advance cardiomyopathy care in Europe and its Member States. The panel discussion was followed by a Q&A session involving onsite and online participants.

Dr. Enrique Terol, Health Attaché at the Permanent Representation of Spain to the EU, indicated that cardiomyopathies have the characteristics of both major diseases because they affect 1.5 million people and rare diseases in many cases. He then presented some of the key elements of the Spanish cardiovascular plan, which specifically addresses inherited cardiovascular conditions. He underlined that the Spanish strategy is based on a holistic approach to the disease. Furthermore, the Spanish strategy keeps high-risk populations under focus. Delving more into what elements are needed for good cardiomyopathies care continuum, he enumerated equity, a good understanding of the warning signs by primary care physicians, patient-centric care, and access to quality data for strong decision-making.

Speaking about the current work in the Council of the EU on the Council Conclusions on the improvement of cardiovascular health, Dr. Terol welcomed the impressive achievements of the Hungarian Presidency and informed participants that most of the elements that have been discussed during the Summit are included in the current draft. He ended by urging the Commission to take these Council Conclusions into account and act.[1]

> "National strategic plans should take a holistic, comprehensive, and data-driven approach spanning prevention, diagnosis –including proactive screening in high-risk groups–, treatment, and rehabilitation. Equity is key to ensuring that all patients and families can benefit. Since cardiomyopathies have features of both rare and common diseases, expert networks such as the ERN GUART-Heart: European Reference Network for rare and low prevalence complex diseases of the heart are vital to sharing data and expertise"
>
> *Enrique Terol*

1. the Council Conclusions were adopted on 3rd December - https://data.consilium.europa.eu/doc/document/ST-15315-2024-INIT/en/pdf

Mr Matteo Pinciroli, co-founder of the Italian Association for the study and research of cardiomyopathies (AICARM), explained that there exist two different pathways –one that looks into what the patient is exploring (*as is pathway*) and another that focuses on what the patient should be exploring (*to be pathway*). Both pathways share a 7-step approach comprised of pre-diagnosis, diagnosis, lifestyle, regular medicines checks, pharmacological treatments, surgical options, and post-op management. Mr Pinciroli asked to incorporate mental health and counselling into the patient experience.

Talking about the policy landscape in his native Italy, he informed that the Italian Parliament had adopted 3 Resolutions to work towards helping cardiomyopathy care. Moving on, he also asked for harmonised measures regarding the renewal of driver's licenses for patients implanted with defibrillators, greater harmonization for the use of saliva and blood tests, and improved access to genetic testing at the national level. In his intervention, Mr Pinciroli also raised the lack of knowledge about what European Reference Networks (ERNs) such as ERN GUARD-Heart are among the general population, which hampers patients' understanding of how they could benefit them.

"Quality of life matters, especially among young patients. Even therapy can have major impacts on well-being and mental health. For example, cardiac surgery requires extensive rehabilitation."

Matteo Pinciroli

Mr James Kennedy, Advocacy Director at the European Society of Cardiology, presented the European Alliance for Cardiovascular Health (EACH), an informal network of 21 separate organizations related to cardiology, which has advocated for the creation of an EU cardiovascular health plan as well as national health plans and which seeks to raise policymakers understanding of the need to give greater visibility to cardiovascular health on the policy agenda. In this regard, he welcomed the work of the European People's Party (EPP) and the Hungarian Presidency for bringing attention towards cardiovascular diseases. He congratulated this renewed impetus on cardiovascular health and noted that the Commissioner-designate for Health, Olivér Várhelyi, committed to advancing a cardiovascular health plan during his hearing with the Members of the European Parliament (MEPs). Yet, he also brought attention to two topics that in his opinion deserved special attention: rehabilitation, including through mental health support, and advancing testing to increase early diagnosis.

"An EU Cardiovascular Health Action Plan would allow numerous actions to be undertaken. Policymakers must remember there are real people, real lives, behind these actions. It's not a cost but an investment and a key means to reduce the enormous disparities in heart health outcomes that exist across Europe"

James Kennedy

PANEL DISCUSSION 2 – DRIVING NATIONAL POLICY CHANGES TO TACKLE CARDIOMYOPATHIES

The second panel discussion focused on how national initiatives are leading their work at local level to advance cardiovascular health and give more attention to cardiomyopathies.

Ms Ester Costafreda, co-founder of the Spanish organisation for arrhythmias associated with sudden death (SAMS), presented the activities and programs that her association are doing in Spain, which include the presentation of Cardiomyopathies Matter's Roadmap in the Spanish Senate. Engagement is also being pursued at the regional level given the fact that health is a full competence of the Autonomous Communities. During her intervention, she also outlined the key elements of the Spanish Action Plan, which includes measures such as a protocol on sudden death, psychological counselling for families, and the creation of more arrhythmia units in the country. Finalising her intervention, she recommended that cardiovascular health plans envisage protocols for sudden death in order to prevent further deaths in the same family.

Dr Rogier Veltrop, from the LMNA lab mechanobiochemistry and cardiac cell signalling, Department of Biochemistry, cardiovascular research institute Maastricht at Maastricht University, The Netherlands, delved into the particularities of LMNA gene mutations, which create different kinds of cardiovascular issues, and family, having been the cause of death of several members of his family. He explained that his organisation works to bridge the gap between all the stakeholders and keep patients' needs at the centre of care. In his intervention, he emphasized the need for more patient involvement at the core of the drafting of care guidelines, especially regarding rehabilitation and mental health. Similarly, he urged for more collaboration between laboratories and better spending of financial resources. Concluding his remarks, he noted that the current rules under the General Data Protection Regulation (GDPR) are too strict and hamper research, so he called for more flexibility in this regard.

"We certainly need more funds for research, but we can also make better use of the funding we receive. Greater collaboration and sharing of data and research technologies, for example to produce stem cells, could greatly improve the efficiency of research spending."

Rogier Veltrop

Speaking about the current landscape in France, Prof. Jean-Noël Trochu, informed that there have been three National Public Health Plans for Rare Diseases, allowing, in the field of cardiovascular diseases, the implementation of the care network Cardiogen. The first plan began dates back to 2005 and the latest one was launched in 2018. As a result, Prof. Trochu deemed that the adoption of the national plan has had a huge impact on improving patient care, for example through the creation of the Cardiogen reference centres, even though diagnosis remains difficult and much remains to be done.

"The French reference centres for inherited cardiac diseases' (Cardiogen) have a huge effect on the quality of patient care, on the level of information provided to patients, and on research. However, there is still much to do, especially to promote early diagnosis and improve the referral pathways from primary care."

Prof. Jean-Noël Trochu

Mr Matteo Pinciroli, co-founder of the Italian Association for the study and research of cardiomyopathies (AICARM), touched upon the launch of Cardiomyopathies Matter in Italy, which was held in the Italian Senate in March 2024, securing a commitment by the Italian Senate to work in the harmonization of driving license regulation for patients with implanted pacemakers. He also added that work happens at the national level and plans at the national level need to go in the same direction that European plans. Inspired by the success of the Spanish chapter, Mr Pinciroli informed that courses on cardiopulmonary resuscitation in schools have been launched in Italy too. He stressed the importance of drawing inspiration from successful national initiatives. As a policy recommendation to conclude his intervention, Mr Pinciroli asked for cardiovascular health checks for the general population.

Prof. Stefan Janssens, Head of the Cardiovascular Disease Department at the University Hospital UZ Leuven, Belgium, spoke about how the lack of a current federal government is making the launch of a national Cardiovascular Health Plan difficult in Belgium. While providing details about the general landscape in the country, he flagged that the biggest problem is awareness, thus demanding solid data access and data sharing similar to Scandinavian countries to build a compelling case that can convince politicians to act. Speaking about innovation, Prof. Janssens called for more collaboration to spread innovative treatments to patients and noted that there is readiness in the research world to undertake a 'radical sharing'. This collaboration could also be orientated towards access to clinical trials. However, for this to happen, the EU institutions should allocate more funding for collaborative research programmes.

"Raising awareness about cardiomyopathies among the public is important to build support for greater investment. Greater collection and sharing of solid data is critical to support policy change."

Prof. Stefan Janssens

CLOSING REMARKS

Member of the European Parliament (MEP) Tomislav Sokol closed the meeting by emphasizing that cardiomyopathies affect around 1.5 million Europeans and are a leading cause of cardiac death in young people. He also drove attention towards the importance of using high-quality data to make progress in tackling cardiomyopathies. In this context, the creation of a European Health Data Space (EHDS) will support those efforts. More specifically on cardiovascular health, he deemed it necessary for the EU to have a separate cardiovascular plan, as acknowledged by the Commissioner-designate Olivér Várhelyi. However, he noted that the key issue will be to secure sufficient funding for its implementation, particularly as regards screening. Given the recent cuts to the EU health budget, MEP Sokol urged to reverse such cuts to ensure that the EU can make the investments that such a plan would entail, for example in prevention, screening, expert centres, and research.

> "More broadly, improving the heart health of Europeans demands a specific, concrete strategy with ambitious funding and benchmarks. This is why I firmly believe we need a separate Cardiovascular Health Strategy similar to the EU Beating Cancer Plan."
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> *MEP Tomislav Sokol*

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