



The Heart Failure Policy Network

Event Report

‘Bringing heart failure into mainstream health policy’

World Heart Day, Tuesday 29 September
European Parliament, Brussels



On the 29th September 2015 (World Heart Day), patients, parliamentarians, and clinicians came together to demand greater recognition for heart failure (HF): a debilitating and costly condition, the prevalence of which is set to increase in the future.

Members and supporters of a new cross-sectoral alliance, the Heart Failure Policy Network, issued a ‘wake-up call’ for governments across Europe in the form of a ten-point Call to Action on Heart Failure, and a supporting HF Policy Toolkit.

For a video summary of the event, presentation slides, and other supporting resources, see: www.hfpolicynetwork.eu/launch2015

To sign the Call to Action, please see: www.hfpolicynetwork.eu/call-to-action



“We have a unique chance to get people together, as politicians our priorities and actions have consequences for patients and healthcare professionals alike. It is important to involve all stakeholders, and the HF Policy Toolkit represents an important step in transforming HF into a national priority in every country.”

Annie Schreijer-Pierik MEP (Netherlands)



“We are inviting people from all over Europe to sign the Call to Action, and to help focus governments on this critical issue.”

Nick Hartshorne-Evans, CEO, The Pumping Marvellous Foundation

World Heart Day, 29th Sept 2015:

Members and key supporters of the HF Policy Network launch a new Call to Action in the European Parliament



From left to right: Ed Harding (Secretariat), Dr Pierre Troisfontaines (cardiologist, Belgium), Dr Philippe Blouard (cardiologist, Belgium), Dr Alan Haycox (University of Liverpool, UK), Deputy Seán Kyne (TD, Ireland), Nick Hartshorne-Evans (The Pumping Marvellous Foundation, UK), Emily Kell (Secretariat), Marie Bolster (Secretariat), Dr Stefano Corda (designated observer, Novartis Pharma AG), Jean Leonard (ASPIC, France), Dr. Suzanne Wait (Secretariat), Pascal Garel (HOPE), Annie Schreijer-Pierik MEP (The Netherlands), Aurélien Perez (DG Santé, European Commission), Aldo Patriciello MEP (Italy), Professor Giovanni De Gaetano (IRCCS Istituto Neurologico Mediterraneo NEUROMED Italy), Oberdan Vitali (Associazione ASIC, Italy), Angela Graves (Pumping Marvellous Foundation, UK), Dr Mark Dancy (cardiologist, UK), Manuela Impellizzeri (Associazione ASIC, Italy), Neil Johnson (National Institute for Preventative Cardiology, Ireland), Deborah Budding (patient representative, the Netherlands), Jayne Knowles-Smith (patient representative, UK), Emilia Belfiore (R&D manager NEUROMED, Italy), Ludovica Moccaldi (St Jude Medical), Claudia Samson (St Jude Medical), Sebastian Gaiser, (designated observer, St Jude Medical).

Why HF?



“HF is unique in that good treatment probably saves money as well as supporting longer and better lives for the patients. Yet the frustrating thing is that we know what works, but we just don’t do it.”

Dr Mark Dancy, cardiologist (UK)

Delegates heard how HF affects 15 million people across Europe, with 1 in 5 of us at risk of developing HF in our lifetime. HF is one of the few cardiovascular conditions where prevalence is rising, potentially by as much as 25% by 2030.

Yet despite its strategic significance and high cost to society, HF remains a forgotten condition by policy makers – and is largely unknown by the general public. Few countries feature HF in their cardiovascular health strategies. What’s more, HF is often considered to be a lost cause, when in fact much can be done to save lives and improve the quality of life for those affected. Many patients do not receive appropriate diagnosis and care, leading to avoidable patient suffering and expensive hospital admissions.



Delegates are presented with the case for change in HF.

Why HF? Some key facts and figures

At least

15 million

adults live with
HF in Europe¹



1 in 5 adults
are at risk
of developing
HF over their
lifetime²

And it's getting worse

Country	% change in of hospitalisations	Time period
France	14.4	2002 to 2008
Germany	39.8	2000 to 2007
Netherlands	21.0	2000 to 2010
Norway	2.4	1999 to 2008
Spain	22.3	2000 to 2011
Sweden	11.4	2001 to 2011
England	-13.1	2001-02 to 2011-12

adapted from Cowie 2014³

The prevalence
of HF is expected
to increase by 25%
by 2030⁴

25%

To download this and other infographics, go to <http://www.hfpolicynetwork.eu/supporting-resources/infographics/>

1. Dickstein et al. Eur J Heart Fail 2008;10: 933-89.
2. Lloyd-Jones et al. Circulation 2002 106: 3068-72.
3. Cowie et al. ESC HFA 2014.
4. Heidenreich et al. Circulation 2011.

The launch of the Call to Action and HF Policy Toolkit

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“This event marks an important moment; the coming together of over a year’s work between our many members. This new and innovative toolkit is a springboard for the future, and I hope we all put it into action in our respective countries and regions. The role of politicians in this debate is essential; we are writing the agenda of the next generation of healthcare policies.”

Aldo Patriciello MEP (Italy)

To challenge the current lack of awareness of HF, the HF Policy Network launched a **Call to Action on HF**, demanding governments deliver on ten key priorities to help prevent, diagnose, and manage the condition more effectively.

Members and key supporters took to the podium to highlight the case for change in HF, before the session was opened up for public questions and answers.



The events' introductory speakers launch the Call to Action; from left to Dr Pierre Troisfontaines (cardiologist, Belgium), Aldo Patriciello MEP (Italy), Nick Hartshorne-Evans (The Pumping Marvellous Foundation, UK).

Aldo Patriciello MEP (Italy), a Network member and official co-host of the event opened proceedings by welcoming delegates and fellow members to the European Parliament, highlighting the importance of this event to improve the positioning of HF in the policy landscape.

Nick Hartshorne-Evans of the Pumping Marvellous Foundation (UK), President of iHHUB (International Heart Hub), a global patient advocacy group in HF and Network member presented his own experience of HF as a patient, as well as screening a video of other patient testimonials. He emphasised how multidisciplinary person-centred care can greatly improve quality of life for patients and discussed the lack of psychological and emotional support most patients receive. Care of HF patients should be viewed holistically; *“everything we do in HF should be for the benefit of the patient and the quality of life for the patient”*. He urged that *“everybody in this room has a responsibility to go out and talk more about HF”* in order to raise awareness of this debilitating chronic condition.

Introducing the Call to Action and the HF Policy Toolkit:



“Today we are calling for action – we are giving decision makers a toolbox, with initiatives, concrete examples and facts regarding heart failure, in order to help the condition to become an urgent policy priority at the European level, and within member states and regions.”

Dr Pierre Troisfontaines, cardiologist and Vice-President of the Belgian Working Group on Heart Failure (Belgium)

Dr. Pierre Troisfontaines, a cardiologist Vice-President of Belgian Working Group on HF and member of Mon Coeur Entre Parenthèses, (Belgium) formally introduced the **Call to Action** and the **HF Policy Toolkit**, detailing the 10 priorities for action, and the contribution of each to the improved care and management of HF.

Dr Troisfontaines declared that “*HF is one of the biggest threats to our health systems*”, explaining that the HF Policy Toolkit was developed to address this threat and to inform and engage decision-makers to help them bring about policy change. The HF Policy Toolkit may act as a powerful tool to initiate a new dialogue with multiple stakeholders throughout Europe.

He spoke particularly of the low awareness of HF at all levels, including a poor understanding of how it fits in within heart disease as a whole.

Dr Troisfontaines then discussed the Charter for HF in Belgium as an example of clinicians, patients and other key stakeholders calling politicians to action. To date, more than 12,000 Belgians have signed the Charter.

Right: Dr Troisfontaines introduced the HF Policy Toolkit and the Call to Action: containing 10 actions every government can take to drive sustainable, high quality care and management of HF.



Call to action

We call upon governments across Europe to commit to improving the lives of people living with HF by focusing on the following priority actions:

Make HF a national priority

- 1 National HF strategies with measurable goals
- 2 Public awareness campaigns
- 3 Data-driven resource planning

Ensure timely diagnosis and prevention in those at risk

- 4 Better professional training in HF diagnosis and management
- 5 Availability and reimbursement of diagnostics

Deliver multi-disciplinary, person-centred care

- 6 A standardised HF pathway that reflects clinical guidelines
- 7 A dedicated contact for follow up care after leaving hospital
- 8 Person-centred care plans focused on improving quality of life

Invest in tools and resources in primary care

- 9 Better workforce planning in primary care to provide comprehensive care for HF
- 10 Investment in innovative tools that promote self-care

Panel debate

Following the introductory speakers, a panel of members and key supporters joined the podium to lend their support to the launch. Each provided some short personal perspectives of the key issues at stake in HF, and how the Call to Action and HF Policy Toolkit can contribute to driving policies forwards.

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“Policy makers and politicians need high quality data with which to scrutinise health outcomes, and guide new policies to improve the treatment, care and quality of life for people living with HF. There is no doubt in my mind that the toolkit will make a difference, most importantly to patients.”

Dr Ian Duncan MEP (Scotland, UK)



Members of the HF Policy Network on the podium for the public discussion; from left to right:

Dr Pierre Troisfontaines (cardiologist, Belgium), Aurélien Perez (guest speaker - DG SANTÉ, European Commission), Pascal Garel (HOPE, Belgium), Nick Hartshorne-Evans (The Pumping Marvellous Foundation, UK), Annie Schreijer-Pierik MEP (The Netherlands), Dr Mark Dancy (cardiologist, UK), Aldo Patriciello MEP (Italy).

Dr Ian Duncan MEP, moderating the panel session, said that this meeting was a unique opportunity to make HF a national priority in every country across Europe. To be effective, this may require a multitude of different strategies and policies.

Dr Mark Dancy, a cardiologist, stated that there needs to system changes at all levels to improve outcomes, and accurate information provided to decision makers as well as patients and healthcare professionals. He declared that *“HF is unique in that good treatment probably saves money as well as supporting longer and better lives for the patients”*.

Annie Schreijer-Pierik MEP discussed the importance of collecting high quality data in order to mainstream HF as a national priority. She emphasised the role that central policy makers could play in driving change across healthcare systems and ensuring a focus on the quality of life for patients at all stages.

Pascal Garel, from the European Hospital and Healthcare Federation (HOPE) stressed how the coordination and planning within healthcare systems was key for the future. He stated his confidence that encouraging hospitals to work towards health promotion and HF prevention at all levels will result in improvements in outcomes and patient care. Often this will involve increased investment and this sort of reorganisation will take efforts from all stakeholders, but are more than worthwhile.

Aurélien Perez provided the European Commission perspective, and discussed the importance of increased training, education and communication between patients and their medical teams. Strengthening the patient role by allowing them to become active in their own care plans and self-management will be important in the future.

Question and answers with delegates

Following the panel session, there was a lively debate during a question and answer session.

Dr Giovanni de Gaetano, Director of Epidemiology from the IRCCS Istituto Neurologico Mediterraneo NEUROMED (Italy), stressed the importance of prevention and prediction of HF. Prevention through lifestyle changes will be important in patients in whom it can make a difference, but engaging in early diagnosis is also vital.

Dr Alan Haycox, a health economist from the UK, posed a question to the panel asking if it were “*lack of knowledge or lack of resources*” that was the biggest barrier to improving HF policy and outcomes.

“We’re wasting a lot of money getting it wrong. Let’s invest a little bit of money in getting it right.”

Dr Alan Haycox, Health Economist, Liverpool University (UK)



Starting the responses from the panel, **Dr Mark Dancy** emphasised that the research base for HF is well established, but the application needs to be improved. Particularly, a lot of lives could be saved if the available drugs were implemented appropriately.

Annie Schreijer-Pierik MEP added that prevention, adequate funding, and the right treatment for patients were key in looking forward, and that there are many unexplored routes of influence which may be opportunities for positive behaviour change, such as the relationship between employers and their employees.

Dr Pierre Troisfontaines stated that the evidence shows that 30-40% of the costs of HF can be saved, and that this evidence had been available for many years, yet many countries do not utilise this information. The knowledge is there, just not the application, and there are differences from country to country regarding health system data, how much is available, and the extent to which it is used to guide improvement.

“Across Europe, therapeutic education for patients must be automatic after a cardiac event or a diagnosis of heart failure.”

Jean Leonard, patient representative, ASPIC (France)



Returning to delegates for more question and comments, **Jean Leonard**, a patient representative from ASPIC in France, wanted to look at system improvements from the patient's perspective. He emphasised the need for strong psychological support for patients and their families. In conjunction with this, medical education programmes would be important to help patients understand their condition and what they can do to help themselves. A strong formal and informal support system will enable patients to make the necessary lifestyle changes that are important in self-management of HF.

Dr Philippe Blouard, a cardiologist from Belgium, highlighted the role of ageing and how health systems need to adapt to the increasing strains on the health system posed by HF. The role of patient education and effective self-management may help reduce this possible future pressure.

Ber Oomen from the European Specialist Nurses Association (ESNO) suggested that there should be greater awareness and training in HF for nurses.

“I think it is very good to have brought this campaign to the wider public, for nurses there must be a much greater awareness, we must bring HF into nurse training activities.”

Ber Oomen from the European Specialist Nurses Association (ESNO)

A small, square portrait of Ber Oomen, a man with glasses and a light-colored shirt, speaking into a microphone.

Oberdan Vitali, a patient representative from Italy, stressed the importance of providing family members with a greater understanding of HF, and ensuring that patients continue living their lives and not be controlled by HF.

Making the closing remarks of the question and answer session, **Aldo Patriciello MEP**, stressed of much greater awareness of HF at the institutional and policy level, in conjunction with increased investment in research.

To conclude Ed Harding, speaking on behalf of the Secretariat of the HF Policy Network, thanked Members and delegates for attending and for helping to make the event a success. He expressed particular gratitude to Aldo Patriciello MEP and Annie Schreijer-Pierik MEP (and their office teams) for their help and support.

Finally, he emphasised the unique, cross-sectoral nature of the Heart Failure Policy Network and the powerful opportunity this new consensus presents to move the debate on HF forward, and invited everyone present to attend next year, on World Heart Day 2016.

Capturing the moment and discussing next steps



A selection of pictures after the event - clockwise from top left: Oberdan Vitali (patient representative, Italy) with Jean Leonard (patient representative, France); Dr Pierre Troisfontaines (Cardiologist, Belgium); Neil Johnson (National Institute for Preventative Cardiology, Ireland) with Deputy Séan Kyne (TD, Ireland); Deborah Budding (patient representative, The Netherlands); Jayne Knowles-Smith (patient representative, UK); Aldo Patriciello MEP with Prof. Giovanni de Gaetano (Italy); and Nick Hartshorne-Evans (Pumping Marvellous Foundation, UK).

To find out more about the
HF Policy Network and the HF Policy Toolkit, go to
www.hfpolicynetwork.eu.

Please join us in signing the call to action, on:
www.hfpolicynetwork.eu/call-to-action