The Heart Failure Policy Network

Helping advance meaningful policy change on heart failure

www.hfpolicynetwork.eu

February 2016
Overview

The Written Declaration 0110/2016 on heart failure closed with 234 signatures on the 24th January.

By many measures, it has been the largest political campaign on HF ever. Key points of success during the campaign from October 2016 through January 2017 are:

Launch

• Declaration was initiated by 17 MEPs, all of which engaged with the campaign throughout.
• 10 MEPs (or their representatives) attended a launch event on October 19th 2016, in the EP in Brussels.
• Participation in the launch event by secured for the ESC HFA, WHF, and European Commission amongst the 60 delegates.

Campaign

• New MEP champions were recruited as campaign champions, many of the 234 signatories engaged with great interest.
• 25 NGOs, professional groups and patient organisations from across Europe formally joined the campaign and promoted the WD directly to MEPs.
• MEP Edward Czesak asked an official question about heart failure to the European Commission.
• EU Commissioner for Health Vytenis Andriukaitis met the Lithuanian Heart Failure Association (ŠNSA) and tweeted his support for the Written Declaration.
• The Declaration was presented to The Maltese Health Minister Chris Fearne during an ENVI committee meeting, and clarification was requested on how CVD and HF will be priorities with the Maltese presidency.

Media

• We reached 1.6 million people with our Tweets and 600,000 people saw our campaign hashtag #SaveHearts.
• Supportive articles were secured in Parliament Magazine, Eurativ, and with notice in Dodds and various EU calendars. We also featured in newsletters for a number of supportive NGOs.
1. About the Written Declaration
2. 19th October launch event
3. Signatures and key outcomes
1. About the Written Declaration
The Written Declaration

The Commission is called upon to consider initiatives aiming to:

- Encourage Member States to create comprehensive national plans to drive improvement and collect adequate data on HF;
- Create a Europe-wide strategy to support public awareness, patient advocacy, and exchange of research and best practice in HF;
- Support training on HF among GPs and internists, and specialisation and accreditation of training for nurses and allied health professionals.

Available in 23 languages!
Initiating MEPs

17 co-signatories from 12 different countries and 4 parties

Andrey Kovatchev  Bulgaria
Aldo Patriciello  Italy
Nicola Caputo  Italy
Cristian-Silviu Bușoi  Romania
Daciana Sârbu  Romania
Victor Negrescu  Romania
Monica Macovei  Romania
Ian Duncan  Scotland
Sirpa Petikäinen  Finland
Marc Tarabella  Belgium
Pascal Arimont  Belgium
Stelios Kouloglou  Greece
Miriam Dalli  Malta
Karin Kadenbach  Austria
Nessa Childers  Ireland
Patricija Šulin  Slovenia
Annie Schreijer-Pierik  Netherlands
Supportive organisations

And several more ‘unofficial’ supporters
New hard copy materials distributed

A3 posters
6 advertising posters were distributed across the European Parliament to raise awareness of the launch. 10 advertising posters were distributed to raise awareness of the Written Declaration.

Fliers
Over 2,000 fliers heart shaped fliers were distributed to MEPs.

HF Infographic
Over 2,500 infographics on heart failure in 10 European languages were distributed.

Supporter flier
Approximately 1,000 fliers featuring logos of our supporters and a quote from iHHub were used in the campaign.

Agenda
Launch specific materials to support the event.

Diagnosis summary
Launch specific material to support the event and raise awareness and increase understanding of HF amongst attendees.
New online materials

Various Twitter graphics
Many Twitter graphics were developed across the campaign to allow Twitter users to demonstrate their support and for the Network to express gratitude.

HF statistic graphics
For all EU countries, a statistic graphic was used to engage MEPs and supporters as well as to raise awareness of the burden of HF in each country.

MEP campaign video
Featuring clips and messages from 8 co-author MEPs. Disseminated 5th December.

Website resources
Comprehensive campaign home with information on how to participate and graphics showing the number of MEP signatories from each country.
The EP environment

Unfortunately, it appears all Written Declarations launched in autumn 2016 experienced a difficult campaign environment.

Vote to end Written Declarations
The Parliament voted to abolish Written Declarations on December 14th, the vote was passed by a large majority of 476 MEPs to 181 MEPs.

What was the impact? During out outreach, many MEPs stated their interest and support for heart failure, but refused to sign as they felt that Written Declarations are not a useful mechanism. This sometimes extended to whole parties or groups within a national delegation.

However, a number of MEPs who were sceptical of Written Declarations did sign WD 110/2016.
2. 19\textsuperscript{th} October launch event report
Key achievements from launch event

The build up and outreach for the event constituted a significant early awareness raising activity within the European Parliament and EU institutions

Successes include:

✓ 60 MEPs were invited to join the tabling of the Written Declaration via personalised emails and follow up calls.
✓ 100 MEPs received personalised emails and follow up calls to join the launch event.
✓ 751 ‘Save the Date’ fliers distributed to MEP pigeonholes.
✓ Formal support of MEP Patient Access Group
✓ Support from both co-chairs of MEP Heart Group and a Vice President of European Parliament
✓ Supportive tweet from EU Health Commissioner Vytenis Andriukaitis
✓ Article in Parliament Magazine by Annie Schreijer-Pierik
✓ Press release with Euractiv
✓ All MEPs emailed twice by Annie Schreijer-Pierik’s office
Members and supporters of the HF Policy Network – including MEPs, patient representatives, and clinicians – gathered in the European Parliament on the 19th October 2016 to discuss policy challenges in HF and to launch the Written Declaration on Heart Failure

The Written Declaration was successfully tabled on the 24th October 2016 (designated number: 0110/2016)

For more information see www.hfpolicynetwork.eu
Annie Schreijer-Pierik MEP was the host for the launch event, which saw over 60 delegates from across Europe pledge their support for the Written Declaration on Heart Failure.

Speaking at the event were:

- **Professor José Ramón González Juanatey**, Cardiologist and Past-President of the Spanish Society of Cardiology
- **Professor Giuseppe Rosano**, the Heart Failure Association of the ESC
- **Dr Pierre Troisfontaines**, Belgian Working Group on Heart Failure
- **Ms Ingrid Keller**, DG Sante

The event then moved onto a panel debate and Q and A session with:

- **Johanna Ralston**, CEO, World Heart Foundation
- **Ber Oomen**, Executive Secretary, European Specialist Nurses Organisations
- **Neil Johnson** CEO, Croí and National Institute for Preventive Cardiology, Ireland

The evening concluded with **Jean Leonard** from ASPIC the French patient group declaring his support for the initiative on behalf of the many HF patients in the room and **Dr Cristian Silviu Busoi MEP** and **Ms Karin Kadenbach MEP** urging their MEP colleagues to sign the declaration.
Social media analysis from the event

By many measures the month of October ‘16 was the best month to date for the HF Policy Network.

Organic impressions for the event totalled **15,300** and we had **108** Re-Tweets!

In terms of engaged audience and reach we surpassed both World Heart Day and HF Awareness Day.

This demonstrates the power of a broad group of supporters who are very active and identify closely with the campaign and HFPN programme.
Twitter screenshots

Aldo Patriciello @PatricielloAldo · Oct 19
Tonight we present the written declaration on #heartfailure @HFPolicyNetwork with @AnnieSchreijer @karinkadenbach @MEPHeartGroup

@MEPHeartGroup

You Retweeted

You Retweeted

You Retweeted

You Retweeted

You Retweeted

You Retweeted

You Retweeted

You Retweeted

You Retweeted

You Retweeted
Twitter screenshots (cont)

Thank you @AnnieSchreijer & all supporting MEPs for launching the Written Declaration on heartfailure on Weds 19 Oct! #SaveHearts @GlobalHF

 Vytenis Andriukaitis @V_Andriukaitis · Oct 19
❤️ starting day w LT heart failure assoc. 1 in 5 europeans at risk! integrated #healthcare & #prevention needed to minimise risk!
👉 You and EU_Health

Ingrid Keller of @EU_health is sharing the EU approach to preventing & managing chronic diseases EUhealth #HeartFailure

Prof. Giuseppe Rosano of @escardio sharing recommendations for best practice & guidelines on #HeartFailure policy to #SaveHearts
3. Key outcomes:

Signatures and key social media outcomes
Key achievements – MEP signatures

In terms of number and origin of MEP signatures, successes include:

- 31% of all MEPs signed the Written Declaration
  - 100% of all Irish MEPs
  - Over 50% in Bulgaria, Croatia, Cyprus, Lithuania, Malta and Romania
- 45% of ENVI committee – signature from outgoing chair and verbal support from incoming chair
- 59% of Heart Group – including both co-chairs MEP Kadenbach and McGuinness
- 4 Vice-presidents of the European Parliament
Signatures by political party

Signatories to Written Declaration 110/2016 by political group

- ALDE
- ECR
- Greens/EFA
- EFDD
- ENF
- EPP
- GUE/NGL
- NI
- S&D

Signatories to Written Declaration 110/2016 by gender

- Male
- Female
Parliamentary questions are questions addressed by MEPs to other European Union Institutions, which must subsequently respond.

Question for written answer to the Commission
Rule 130
Edward Czesak (ECR)

Subject: Heart failure

Heart failure is currently regarded as one of the most common diseases in our society, and complications from it are the most frequent cause of deaths. Symptoms of heart failure affect 15 million Europeans, and heart failure is the most frequent cause of hospitalisation in those over 65. Worrying trends indicate that without concerted prevention, heart failure cases will increase by 25% by 2013. The data justifies taking action to build a common strategy to meet this challenge.

The risk and burden of heart failure can be significantly reduced through multidisciplinary care. Heart failure patients often do not receive quality care in accordance with recognised clinical guidelines. It is also important to support common actions to raise public awareness of the dangers posed by this disease. The analyses that have been carried out show that few governments have adopted national heart failure plans.

In this connection:
1. Does the Commission intend to take steps to support and encourage Member States to create comprehensive national plans to improve the current situation and to prevent worrying prognoses?
2. Does it intend to create a Europe-wide strategy to support public awareness, patient advocacy, and exchange of research and best practices as regards heart failure?
3. Does the Commission intend to take specific steps to support the training of healthcare professionals on heart failure?

Last updated: 4 January 2017

Click here for full Written Question and Answer
The Commission addresses the prevention and management of chronic diseases in a holistic manner, including by addressing the risk factors which are common to various diseases.

... the Commission supports Member States in their efforts to tackle chronic diseases and disorders, including heart failure. The Commission has presented such action at a recent event on heart failure hosted in the European Parliament in October 2016.

The Commission is supporting a joint action on Chronic Diseases (CHRODIS) which has developed an IT platform with best practices... [and] a training programme for managers of multi-morbid patients, reflecting the integrated approach to chronic diseases.

Furthermore, over EUR 4 billion have been devoted to ... chronic diseases under the Horizon 2020 Programme....In particular, 18 projects worth EUR 29.6 million address heart failure research. More information about current funding opportunities can be obtained at the Research and Innovation Participant Portal.
On the 24th of January, at the ENVI committee meeting Annie Schreijer-Pierik made a concluding remark to the Committee and Dr Chris Fearne, Maltese Minister of Health.

A Written Declaration advocacy pack and ceremonial poster was provided to Dr Fearne and he was invited to participate in a group photograph with some of the initiating MEPs.

A brief press release was distributed on Dods’ services on 1st February and to all MEPs in the legislature on 2nd February.
Twitter mentions & reach

1.6 million users reached with @HFPolicyNetwork tweets

589,534 users reached with #SaveHearts tweets

152,210 users reached with #ChangeHFpolicy tweets

Timeframe: 27 September 2016 – 27 January 2017
Twitter mentions by country

Mentions of @HFPolicyNetwork

- UK: 23%
- Belgium: 21%
- France: 19%
- Netherlands: 8%
- Ireland: 8%
- Other: 9%
- Italy: 3%
- Spain: 3%
- Belgium: 1%
- Other: 1%

Mentions of #SaveHearts

- UK: 28%
- Belgium: 22%
- France: 14%
- Other: 9%
- Ireland: 8%
- Netherlands: 8%
- Switzerland: 5%
- Italy: 3%
- Spain: 3%
- Other: 1%

Mentions of #changeHFpolicy

- Ireland, 34%
- Belgium, 12%
- Netherlands, 17%
- France, 10%
- Other, 8%
- Netherlands, 9%
- UK, 22%

- High quality engagement in a wider range of EU countries than ever before.
- Use of #changeHFpolicy shows long term engagement with @HFPolicyNetwork and our messaging.
MEP Twitter engagements
Top sources of Twitter mentions

Top sources by number of tweets mentioning #SaveHearts

<table>
<thead>
<tr>
<th>Top users of #SaveHearts</th>
<th>Mentions</th>
</tr>
</thead>
<tbody>
<tr>
<td>@CroiCharity</td>
<td>15</td>
</tr>
<tr>
<td>@KeesBos1</td>
<td>6</td>
</tr>
<tr>
<td>@thbeckjordenmn</td>
<td>5</td>
</tr>
<tr>
<td>@worldheartfed</td>
<td>4</td>
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<tr>
<td>@iron_deficiency</td>
<td>4</td>
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<tr>
<td>@pumpinghearts</td>
<td>3</td>
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<tr>
<td>@iamnickevans</td>
<td>3</td>
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<tr>
<td>@annieschreijer</td>
<td>3</td>
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<tr>
<td>@patricielloaldo</td>
<td>3</td>
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</tbody>
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Timeframe: 27 September 2016 – 27 January 2017
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