



EUROPEAN HEART FAILURE AWARENESS DAY 2014 REPORT FROM THE BRITISH SOCIETY FOR HEART FAILURE (BSH)

Please find below details of work in the United Kingdom for European Heart Failure Awareness Day 2014.

EVENTS

1 Parliament – political events

a Initial idea, meeting and preparations

BSH Chair, Professor Andrew Clark, met Lord Hunt of Kings Heath (a suburb of Birmingham), the front bench spokesman on health in the House of Lords (the second chamber of UK Parliament) for the Labour Party, to discuss ideas about what the BSH might do for European Heart Failure Awareness Day in 2014. Following the meeting, Lord Hunt agreed to help and took a copy of the National Heart Failure Audit (<http://www.ucl.ac.uk/nicor/audits/heartfailure/documents/annualreports/hfannual12-13.pdf>), promising to raise appropriate questions (see 2 below) with his Chief Executive about the performance of his National Health Service (NHS) Trust and to ask questions in Parliament. Lord Hunt also advised that he would be prepared to stage a half-hour debate in the Lords.

Letters were sent to the local MPs of all BSH Board members to bring European Heart Failure Awareness Day to their attention (see page 16 of Appendix for sample).

b Scottish Parliament, Holyrood, Scotland (<http://www.bsh.org.uk/meetings/bsh-parliamentary-events/scotland-parliamentary-event/>)

[See appendix: page 9 on site pack; page 18 folder; pages 19-20 pledge card, page 21 letter, page 22 agenda, page 23 biographies, pages 24-25 what is ..., page 26 questions asked, page 27 delegate list]

An event was held on Tuesday 6 May 2014 in the Scottish Parliament at Holyrood for Members of Scottish Parliament (MSPs) and others responsible for public policy to raise awareness of heart failure in Scotland. Jim Eadie MSP (see page 10 of Appendix) sponsored and supported the meeting.

Objectives

The key objective of the Scottish parliamentary event was to mark European Heart Failure Awareness Day and to raise awareness of heart failure among Scottish politicians and others responsible for public policy.

The main focus being as follows.

Prevalence & Cost – Heart failure is more common than many would believe. It affects nearly 3 in every 100 women and 4 in every 100 men. It accounts for 5% of all emergency hospital admissions and 2% of all NHS hospital bed days.

Quality of Life – Heart failure causes greater reduction in quality of life than any other chronic medical condition. Inadequately treated heart failure has a similar survival rate to many forms of cancer.

Treatment – With appropriate treatment, survival rates and quality of life for patients dramatically improve. Patients need to be on the right pathway and have access to the most appropriate therapies and treatments.

Political Engagement – Scottish health services have engaged successfully with heart failure practitioners and patients, but more needs to be done. The BSH is working with Scottish clinicians who are driving improvement in heart failure care through the Scottish Heart Failure Hub (a subgroup of the National Advisory Committee for Heart Disease).

Attendance

The event was attended by MSPs, policy makers, patients, patient organisations, healthcare professionals, the Scottish Heart Failure Hub and industry representatives.

Politicians were able to mingle with clinicians and patients during the two-hour event, hearing what is important to them and gaining a better understanding of the issues for heart failure patients and for those treating them. The BSH Board members explained and demonstrated equipment used in the diagnosis and treatment of heart failure, and politicians were even able to try their hand at carrying out an echocardiogram (on a volunteer research fellow) which was very popular with the politicians (see page 11 of Appendix). They were also asked to sign a pledge supporting the need for raising heart failure standards (see page 8 of Appendix).

Presentations

Short but highly persuasive talks were given during the event by clinicians in the heart failure area (see pages 14 and 15 in Appendix) and by patients who shared their experience and stories of living with heart failure (see pages 12 and 13 of Appendix), providing a particularly powerful message for the politicians present.

Follow up activities

A press release (see page 28 of Appendix) was sent to all attending MSPs for distribution to their local press. Photographs from the event are available on our Facebook page at <https://www.facebook.com/photo.php?fbid=764400550257961&set=a.764400533591296.1073741830.636786013019416&type=3&l=5d39e90446&theater>.

c UK Parliament, Westminster, London (<http://www.bsh.org.uk/meetings/bsh-parliamentary-events/uk-heart-failure-parliamentary-reception/>)

An event will be held on Tuesday 10 June 2014 in the UK Parliament at Westminster, London for Members of Parliament (MPs) to raise awareness of heart failure in the UK. Neil Carmichael MP is sponsoring and supporting the meeting. This event is linked to the European Heart Failure Awareness Day however can only take place in early June as the formal start of the parliamentary year does not begin until 4 June.

Objectives

To raise awareness in MPs, Peers and policy influencers of the social and financial burden of heart failure in order to prioritise heart failure as a condition and maximise investment into heart failure services.

To highlight to MPs how their own heart failure services have been performing versus other areas of the country and give them the relevant data to take back to their local NHS to discuss how the heart failure service can be improved.

To highlight to MPs, Peers and policy influencers (and through the media) the importance of all areas of the country having a specialist heart failure team that all heart failure patients can be quickly referred to, which would improve patient care and save the NHS money.

Key messages

Heart failure, the inability of the heart to pump effectively, is associated with disabling symptoms and a worse prognosis than many cancers.

Advances in medication, interventions and management by specialist heart failure teams, however, means that:

- patients can be rapidly diagnosed and optimally treated
- survival rates can be significantly improved
- symptoms can be controlled and patients can enjoy a good quality of life
- the burden on hospital beds and emergency admissions can be reduced.

Despite this, access to specialist heart failure teams is inconsistent across the UK leading to variations in emergency hospital admissions, a patient's chance of survival and a patient's quality of life.

All heart failure patients should have access to a specialist heart failure services as recommended by NICE.

Attendance

The event will be attended by MPs, Peers (members of the House of Lords), Dr Dawn Harper (doctor often appearing on television), patients, patient organisations and healthcare professionals.

Interactive stations

There will be a number of exhibition stands at the event as follows.

- BSH stand with heart failure facts and figures
- Echo demonstration
- Heart testing
- Telehealth demonstration

Materials

Local heart failure data will be provided on iPads for each attending MP. National maps will show the prevalence of heart failure and hospital admissions for each constituency. There will also be a photo opportunity for each MP/Peer. Posters displayed at the event will highlight the key heart failure messages and all attendees will be given an information pack, including information on the BSH, heart failure and calls to action. (See pages 33-48 of Appendix for draft materials.)

Presentations

Speeches will be made by Neil Carmichael MP, Professor Andrew Clark (BSH), Mr Harry Prentice (patient), Mr Richard Mindham (patient) and Dr Dawn Harper (GP and TV doctor).

Follow up activities

A variety of awareness activities will follow this event. Activities will include a thank you e-mail and letter to attendees and following collaboration with the local lead clinician, an invitation to visit their local heart failure service may be sent. One to one meetings will also be organised with target MPs.

2 Parliamentary questions

a Asking questions in Parliament

MPs/MSPs and Lords can raise matters in Parliament on behalf of their constituents (those living in the area they represent) by way of asking written or oral questions. The Government is required to answer parliamentary written questions and both the questions and answers are published in Hansard, the official on-line transcript of what is said in Parliament. Parliamentary questions can expose Government failings, raise the profile of an issue or put Government policy on the record.

b Questions asked by Lord Hunt of Kings Heath in sessions at the UK Parliament, Westminster

<http://www.publications.parliament.uk/pa/ld201314/ldhansrd/text/131205w0001.htm#13120558000084> (see Health: Cardiology)

To ask Her Majesty the Queen's Government what action they are taking to ensure an improvement in heart failure services above the standard reported in the National Heart Failure Audit 2012–13.

Answer from Earl Howe, Parliamentary Under-Secretary of State, Department of Health

Responsibility for determining the overall national approach to improving clinical outcomes from healthcare services lies with NHS England. NHS England hosts a number of strategic clinical networks which cover cardiovascular disease and which are intended to support the development and dissemination of good clinical practice.

To ask Her Majesty the Queen's Government what action they are taking to ensure that patients with left ventricular systolic dysfunction are treated in line with National Institute for Health and Care Excellence clinical guidelines.

Answer from Earl Howe, Parliamentary Under-Secretary of State, Department of Health

It is for individual clinical commissioning groups to commission treatment and services for patients with heart failure, as they are best placed to identify what is needed in their local areas, taking into account relevant guidance from the National Institute for Health and Care Excellence.

To ask Her Majesty the Queen's Government what assessment they have made of the adoption by the National Health Service of the Cardiovascular Disease Outcomes Strategy.

Answer from Earl Howe, Parliamentary Under-Secretary of State, Department of Health

NHS England advises that it has established a Cardiovascular Disease Outcomes Strategy implementation group and that it is working with a variety of partners and stakeholders to deliver the strategy.

c Questions asked by Ken Macintosh MSP in sessions at the Scottish Parliament, Holyrood

To ask the Scottish Government how the (a) treatment, (b) care and (c) life expectancy of patients with heart failure in Scotland compares with the rest of the UK.

Answer from Mr Michael Matheson MSP

Scotland has some of the best health service data in the world and on an annual basis produces information on a range of heart conditions in Scotland. There is evidence that life expectancy for people with coronary heart disease, the main cause of heart failure, is increasing year on year in Scotland. Information is not collected centrally to allow statistics on the life expectancy of patients with heart failure to be compared directly with those in the rest of the UK.

Recent data suggests that the number of people surviving 30 days after hospital discharge with a diagnosis of heart failure is also increasing but there is scope for further improvement. The Scottish Government is prioritising Quality Improvement strategies for heart failure and will continue to work with the Scottish Patient Safety Programme to encourage reliable delivery of the Heart Failure Bundle to advance the treatment, care and life expectancy of people living with heart failure across Scotland.

To ask the Scottish Government what action it is taking to improve the treatment and care of patients with heart failure.

Answer from Mr Michael Matheson MSP:

The Better Heart Disease and Stroke Care Action Plan emphasises the Scottish Government's commitment to tackling heart disease as a clinical priority for NHS Scotland and specifically highlights the need for a greater strategic focus on improving the care of people with heart failure.

The Heart Failure Hub has been established as a subgroup of National Advisory Committee on Heart Disease in order to take forward a national programme of work in relation to heart failure. The group brings together clinicians, managers, the voluntary sector and patients to ensure a coordinated approach to tackling the many challenges facing heart failure teams in NHS Boards across Scotland.

To ask the Scottish Government what its position is on the stated benefits of the National Heart Failure Audit.

To ask the Scottish Government whether it is participating in the National Heart Failure Audit and its reasons for its position on this matter.

Answer from Mr Michael Matheson MSP:

Heart disease remains a clinical priority for NHS Scotland and the Scottish Government. There has been substantial investment and redesign in cardiology services which has contributed to NHS Scotland reducing mortality rates from coronary heart disease by over 43% in the last 10 years.

Scotland is not participating in the National Heart Failure Audit which is being carried out in England and Wales. The Scottish Government's preferred approach to supporting improved care for patients with heart failure is to work with the Scottish Patient Safety Programme to encourage consistent delivery of the Heart Failure Bundle across the whole of Scotland.

3 Other events

a Glenfield Hospital – organised local Heart Failure Awareness Day workshop in Leicester.

b NHS Grampian – organised a public and staff information stand at Aberdeen Royal Infirmary (see page 17 of Appendix).

c Southampton General Hospital – held a heart failure rehabilitation programme with the presence of three local MPs.

d West Hertfordshire Hospitals – presented findings of a trial RAHFC launching their heart failure clinical pathway at the Cardiology Clinical Governance meeting on 13 May 2014 (see page 31 of Appendix).

Newspaper and website coverage

1 BSH

- Substantial media coverage (local – using constituency data and MP photographs; medical – letters to editors; social – twitter [[@BSHeartFailure](#)], BSH website [[www.bsh.org.uk](#)], YouTube video) is anticipated subsequent to the UK Parliamentary Event on 10 June 2014.

- Advertised event in *Your Life* magazine (see page 3 of Appendix). Rowland's Pharmacy produces this magazine and 35,000 copies were circulated to 510 pharmacies in the UK.
- Advertised details of the event in all journal articles produced from our Annual Autumn Meeting, Heart Failure Day for Training and Revalidation and Heart Failure Nurse Study Day.
- Placed information prominently on the home page of our website <http://www.bsh.org.uk>.
- Provided details of activities held in both current and previous years on our website as a source of suggestions and ideas <http://www.bsh.org.uk/resources/heart-failure-awareness/>.
- Provided posters for the event via our website (see page 2 of Appendix).

2 NHS Grampian

- Advertised their event at Aberdeen Royal Infirmary in the NHS Grampian *Upfront* magazine (see page 4 of Appendix), their staff intranet and the NHS Grampian Twitter and Facebook pages.
- Garnered more than 50 likes, retweets and favourites on the NHS Grampian Twitter and Facebook pages.
- A follow up article will be placed in the June edition of the NHS Grampian *Upfront* magazine.

3 West Hertfordshire Hospitals

- Advertised details of their heart failure clinical pathway in an e-update newsletter (see page 31 of Appendix).

4 Other

- Article 'Acute heart failure patients should be seen by specialist teams, say NICE' appeared in *British Medical Journal* (see page 6 of Appendix; <http://www.bmj.com/content/348/bmj.g3072>).
- Article 'Heart failure cases do not get specialist care, doctors warn' appeared in *The Guardian* (see page 7 of Appendix; <http://www.theguardian.com/society/2014/may/09/heart-failure-cases-dont-get-specialist-care>).

Printed material for patients

BSH

- Distributed leaflets and business cards for the Heart Failure Association patient website *heartfailurematters.org* at BSH conferences in November 2013 and March 2014 with delegates totaling approximately 950, and at a local Heart Failure Awareness Day workshop in Leicester.
- Mailed all members of the Society (over 1,000) providing information about the European Heart Failure Awareness Day (see page 5 of Appendix).
- E-mailed Friends (pharmaceutical and device companies) of the Society providing information about the day.
- Created high resolution posters (both small and large versions) especially for the UK with our logo and placed these on the same website that HFA used for their own poster.
- Circulated information to other people linked to the Society (private).
- Included information about the day in the delegate packs for delegates attending our Annual Autumn Meeting on 28-29 November 2013, our Heart Failure Day for Training and Revalidation on 20 March 2014 and our Heart Failure Nurse Study Day on 21 March 2014.
- Encouraged participation in the National Heart Failure Audit via mailings to members.
- Provided free access to the *Oxford Textbook of Heart Failure* for all BSH members (see page 49 of Appendix).
- Will advertise details of BSH European Heart Failure Awareness Day activities on a poster (see page 32 of Appendix) and in a leaflet (see pages 29-30 of Appendix) distributed during the British Cardiovascular Society Annual Conference (2-4 June 2014), at which 3000 delegates are expected.
- Working closely with NICE on acute heart failure guideline consultation.

Pumping Marvellous

- Produced *Pregnancy and Your Heart* booklet (see page attached)

Other national initiatives

1 Acute Heart Failure Guidelines

The new Guidelines for Acute Heart Failure will be published in September however the consultation document was sent out to the stakeholders to coincide with European Heart Failure Awareness Day.

2 BSH

- Supported Society members and pharmaceutical/device companies with their plans for the day.
- Provided feedback on consultations with the National Health Services (NHS) and NICE.
- Worked closely with the Cardiovascular Outcomes Group.