

**Cross Party for Heart Disease & Stroke
Annual General Meeting
Wednesday 6th March 2013
Committee Room 5, Scottish Parliament**

1. Welcome & apologies

Convenor, Helen Eadie [HE] MSP welcomed everyone to the first meeting of 2013.

MSP Attendance

Helen Eadie MSP
Richard Simpson MSP
Dave Thompson MSP
Maureen Watt MSP

MSP Apologies

Jackie Baillie MSP
Alison McInnes MSP
Aileen McLeod MSP
Fiona McLeod MSP
Duncan McNeil MSP
Bill Walker MSP

ANNUAL GENERAL MEETING

Financial Return

The draft financial return was circulated to the group, which showed the costs of catering and the contributions from BHF Scotland and Chest Heart & Stroke Scotland who have provided the Secretariat. No donations were received by the group. There were no objections to the return, which will now be submitted to the Scottish Parliament.

Achievements of the past year

The intention of the Secretariat is to compile the key achievements of the group into a document to be shared at the next meeting. Members' were asked to send in contributions for this report.

Nomination and election of Office Bearers

Helen Eadie MSP [HE] introduced the nomination and election process and then stood down to allow for a fair process.

Convenor

The only nominee for Convenor was Helen Eadie MSP; nominated by Dave Thompson MSP and seconded by Richard Simpson MSP. The group approved the nomination and HE was reinstated as Convenor.

Vice-convenors

The only nominees for Vice-Convenors were Dave Thompson MSP [DT] and Dennis Robertson MSP [DR]; nominated by Richard Simpson MSP and seconded by Ben McKendrick. The group approved the nominations and DT and DR were reinstated as Vice-Convenors.

Secretariat

The only nominees for Secretariat were Ben McKendrick [BMcK], BHF Scotland and Louise Peardon [LP], Chest Heart & Stroke Scotland; nominated by Dave Thompson MSP and seconded by Richard Simpson MSP. The group approved the nominations and BMcK and LP were reinstated as the Secretariat.

2. Minutes – Wednesday 28th November 2012

Accepted as an accurate record – proposed by Gordon Snedden and seconded by Kim Hartley.

3. Matters arising

CPG Sub-Group update

Kim Hartley [KH] updated on behalf of the sub-group that work was continuing to refine the patient charter for stroke patients and that organisations were being contacted to endorse the work, with the group also considering a launch and subsequent distribution. The final draft will be brought back to the main CPG for further discussion and endorsement.

Parliamentary Debate on Cardiac Rehabilitation

Copies were circulated of a summary of a debate held on the 24th January 2013, following the cross-party support for HE's Motion to congratulate the British Association of Cardiovascular Prevention and Rehabilitation [BACPR] on the publication of their Standards & Core Components 2012 (as presented at the CPG in October 2012).

The debate was well supported and good natured with all Parties pledging their support for cardiac rehab to be available to all heart patients, the need to audit progress on an ongoing basis and the introduction of a HEAT target to drive improvements. Michael Matheson MSP gave a positive response on behalf of the Scottish Government and referred matters to the National Advisory Committee for Heart Disease. LP is a member of the NACHD and will provide an update on the discussions in due course.

4. Forthcoming Atrial Fibrillation Event

Angie McLeod, The Stroke Association updated the group on an event to be held on the evening of the 16th April 2013, Committee Room 1 at the Scottish Parliament. The event is being hosted by the AF Special Interest Group and is being hosted by Bob Doris MSP.

5. Presentations

HE introduced a series of brief 5 minute presentations from professionals, patients and carers on the topics of specialist nursing care for stroke and specialist nursing care for heart failure.

The value of the Specialist Stroke Nurse

Mr Campbell Chalmers [CC], Stroke Nurse Consultant

CC began with a brief overview as his role as Stroke Nurse Consultant in NHS Lanarkshire and his key roles of being a clinical leader, promoting expert practice, policy, education and research. CC also highlighted the work of the Scottish Stroke Nurse Forum [SSNF], which has over 300 members and has been

established for 10 years to promote quality, education and research. He showed the group the SSNF work plan – copies are available from the Secretariat. CC concluded with a summary of some of the key challenges facing stroke care with advancing technology and treatment and the work of the FAST campaign to raise awareness of the signs and symptoms of stroke.

Mrs Audrey Bruce [AB], Lead Stroke Nurse

AB leads the CHSS Stroke Nurse Service for Lothian. She described the development of the service, to one which is now fully established, looking after over 700 patients per year and seamless with NHS services, with joint working relationships established with health, social care and other voluntary services. AB described the complexity and variety of affects of stroke on an individual and the impact on the wider family and she outlined the holistic model of care, centred around the home where an individual could be realistically assessed and supported in regaining independence, with the service making over 1,000 onward referrals per annum.

Mrs Alison Taylor [AT], stroke patient

AT described her personal stroke journey and the many difficulties and delays that she encountered in receiving the support she needed. She described the importance of information in her understanding her stroke and what to expect and the difficulties she had in accessing this. AT talked about the impact that the Stroke Nurse had on her life, when she was finally referred 5 months after her stroke. She described the subsequent visits and phone calls as turning her life around and that *'my real recovery began when the Stroke Nurse entered my life'* and that her fears and anxieties were listened to and understood.

Mr Neil Shaw [NS], stroke carer

NS described the very positive experience that he and his wife had following her stroke in 2011 and complimented the many professionals who supported them. He emphasised that every stroke is different and that to everyone it is a *'life-changing event'*. NS talked through the couples' experiences since and described the invaluable support and information provided by the Stroke Nurse to assist and guide them in learning to adapt to the changes in their lives. NS summed up the Stroke Nurse role as guiding them as to *'where we are, where we are going and what we can do'*.

The value of the Specialist Heart Failure Nurse

Mrs Janet Reid [JR], Lead Heart Failure Nurse

JR is the Lead Nurse for the Heart Failure Service in Lothian and described why she considers the heart failure specialist nurse role pivotal in the management of heart failure patients. JR gave a profile of those living with heart failure as being over 90,000 in Scotland, with frequent hospital admissions and many other co-morbidities. JR described the technical aspects of the role (e.g. adjusting medication) and the compassionate work to empower the patient and their family to manage the condition; coming to terms with the diagnosis. JR concluded that this valuable role is patient-centred and evidence-based.

Mrs Margaret Young [MY], heart failure patient

MY talked through her complex history, having survived cancer only to be diagnosed with heart failure as a result of the cancer treatment. MY described her many past-times and hobbies and how heart failure had affected her, although she had always tried to maintain her positive attitude to life. MY had reacted badly to many of the heart drugs and she described the essential role of her nurse in monitoring and adjusted her complicated treatment, '*she just knew me so well*' and how after some initial setbacks she was looking forward to getting back to her walking, dancing and golf and getting on with her life.

Mr Thomas Stark [TS], heart failure patient

TS described he and his family's experience of a heart failure diagnosis and his treatment and rehabilitation at Astley Ainslee Hospital. TS had been well supported throughout his time at AAH and described the value of group discussions and listening to the experiences of others, he also shared a moving letter that his wife had written to the NHS to express their thanks. TS summed up the input of the specialist nurse as; '*I'll no beat about the bush but the nurse was our lifeline*'.

Ms Lorraine Jones [LJ], heart failure carer

LJ and sister were both full-time carers for their mum since her diagnosis of end stage heart failure. LJ described the journey that she and her family had been on losing their father and then the impact of their mother's illness, particularly challenging when her mother would not accept the diagnosis. LJ talked about all aspects of the support from their nurse; practical with arrangements for the end of life and emotional in supporting them and helping them to come to terms with what was happening. LJ summed up the support; '*you can't repay what she's done for me and my family.*'

Scottish Heart Failure Nurse Forum [SHFNF] Review 2013

Mrs Suzanne Bell [SB], Chair of SHFNF

SB has chaired the SHFNF over the last 2 years, a membership organisation representing over 50 specialist nurses and covering every NHS Board. She introduced the SHFNF Review 2013 document which has been drawn together by the members across Scotland and provides a snapshot of specialist nursing care for those living with heart failure. SB outlined the key messages of the Review (circulated to the group), which focused on the need to develop the invaluable specialist heart failure nurse services, allow time for the nurses to take part in educational initiatives to share their expertise, promote a palliative care approach, ensure access to cardiac rehabilitation for those with heart failure and ensure adequate administration support for specialist services. SB thanked all the members of the SHFNF for providing the information in the Review and outlined the media coverage it had received since its launch this week.

6. Discussion

HE thanked all the presenters for sharing such meaningful and moving accounts of their experiences and she congratulated the specialist nurses on the level of support they offered. HE stated that it was the MSPs' role to be alert to threats to such precious roles.

Discussion began on the SHFNF Review finding that the numbers of specialist posts in Scotland were dropping, while the numbers of those living with heart failure was increasing. HE suggested that once MSP colleagues had chance to study the report, a letter could be sent to the Cab Sec for Health to ask what was being done to address this decline in numbers.

Members acknowledged the technical knowledge and emotional support provided by specialist nurses and how valuable this was to patients and their families. DT also raised that the shift in the balance of care was primarily concerned with reducing hospital admissions, which specialist roles were achieving, with their effective approach. The group also discussed that investment in specialist roles, was in effect a saving by reducing the need for hospital care.

Susan Kennedy [SK] raised the additional concern of workforce planning and the impact that retiral could have on the experienced body of specialist nurses in Scotland. SB emphasised that specialist nurses are also constantly evolving their roles to meet changing needs and to ensure their sustainability. LJ described her lack of awareness of the costs of services, as from a carer' perspective you are just looking for the support.

HE emphasised the role of local MSPs in supporting constituents with issues that affected people locally, but also could be a common endeavour more widely; using the need to protect specialist nursing services as an example. She also encouraged members to keep pursuing local issues and to come back to the CPG in the future and share their experiences. HE expressed the heartfelt thanks of the group to all the speakers.

7. AOCB

None.

8. Next Meeting Dates

- The next meeting is 1730 for a 1800 start on **Wednesday 5th June 2013**, Committee Room 5.

Additional 2013 dates:

- Wednesday 18th September
- Wednesday 4th December

Non-MSP Attendance

Title	Forename	Surname	Organisation
Mrs	Gillian	Alexander	Scottish AHP Forum
Mr	Iain	Armstrong	Caring Together
Mrs	Suzanne	Bell	Scottish Heart Failure Nurse Forum
Ms	Katrina	Brennan	Scottish Government
Mrs	Audrey	Bruce	Chest Heart & Stroke Scotland
Mrs	Jan	Buncle	Chest Heart & Stroke Scotland
Ms	Marjory	Burns	BHF Scotland
Mr	Campbell	Chalmers	Scottish Stroke Nurse Forum
Mrs	Jane	Chalmers	Chest Heart & Stroke Scotland
Ms	Ann	Christie	Stroke Carer - NHS Tayside
Mr	David	Clark	Chest Heart & Stroke Scotland
Mr	Martin	Coombes	Astra Zeneca
Ms	Eileen	Cowie	Scottish Stroke Nurse Forum
Ms	Anona	Cranston	Scottish Heart Failure Nurse Forum
Ms	Carol	Deighan	Heart Manual Lothian
Ms	Gillian	Donaldson	NHS Borders
Ms	Hazel	Fraser	Scottish Stroke Nurse Forum
Ms	Sandi	Haines	Scottish Stroke Nurse Forum
Ms	Kim	Hartley	Royal College of Speech & Language Therapists
Mr	Brian	Jardine	Irvine Classics Stroke Group
Mr	Richard	Jopling	
Ms	Lorraine	Jones	Stroke Carer - NHS Tayside
Ms	Susan	Kennedy	NHS Education for Scotland
Ms	Karen	Lee	Boehringer Ingelheim Ltd
Mr	Thomas	Marshall	Roche
Ms	Angie	McLeod	The Stroke Association
Ms	Sinead	McKee	Scottish Heart Failure Nurse Forum
Mr	Ben	McKendrick	BHF Scotland
Ms	Jill	Nicholls	Scottish Heart Failure Nurse Forum
Miss	Louise	Peardon	Chest Heart & Stroke Scotland
Mrs	Janet	Reid	Scottish Heart Failure Nurse Forum
Ms	Di	Rennie	Scottish Stroke Nurse Forum
Mrs	Shirley	Roberston	Scottish Heart Failure Nurse Forum
Ms	Delia	Rodgers	Boehringer Ingelheim Ltd
Mr		Shaw	Stroke Carer - NHS Fife
Mrs	Yvonne	Shaw	Stroke Patient - NHS Fife
Mr	Mark	Smith	NHS Lothian
Mr	Gordon	Snedden	Angus Cardiac Group
Mrs	Anne	Stark	Heart Failure Carer - NHS Lothian
Mr	Thomas	Stark	Heart Failure Patient - NHS Lothian
Prof	Allan	Struthers	NHS Tayside/University of Dundee
Mrs	Alison	Taylor	Stroke Patient
Ms	Louise	Taylor	Heart Manual Lothian
Mrs	Jemima	Traill	BHF Scotland
Mrs	Margaret	Young	Heart Failure Patient - NHS Tayside
Mrs	Carol	Walford	
Mr	Stewart	Wood	Medtronic