

Heart Disease & Stroke Cross Party Group
Wednesday 18th September 2013,
Committee Room 5, 1800-2000

Adult Congenital Heart Disease [ACHD]

1. Welcome & Apologies

MSP Attendance

- Helen Eadie (Convenor)
- Nanette Milne

MSP Apologies

- Jackie Baillie
- Margaret McDougall
- Alison McInnes
- Richard Simpson
- Dave Thompson (Vice-Convenor)
- Maureen Watt

HE updated that both Richard Simpson MSP and Dave Thompson MSP were on sick leave and the CPG wished them well in their respective recovery.

2. Minutes: Wednesday 5th June 2013

The minutes were approved by Gordon Snedden and seconded by Carol Walford.

3. Matters arising

- **Secretariat Update (HE)**

HE updated that this is the last meeting for both Ben McKendrick [BMcK] and Louise Peardon [LP]. Ben is leaving BHF to move on to a senior position with charity Myeloma UK and Louise is leaving Scotland and Chest Heart & Stroke Scotland, to pursue personal opportunities in England.

To ensure the continuity of the organisational work behind our Cross Party Group in the meantime, HE met with Laura Hastings (Head of Advice & Information with Chest Heart & Stroke Scotland) and LH has agreed to provide interim support to the group. Both CHSS and BHF have given their commitment to the group and we hope to be able to update again in December.

- **Progress on Specialist Heart Failure Nursing**

LP updated that following the March CPG meeting and subsequent Parliamentary Motion and Debate (Dave Thompson MSP) the Scottish Heart Failure Nurse Forum had been approached by the Chief Nurses' Office of the

Scottish Government. A timetable of joint work was now underway and promises to have great benefits for all specialist nurses in Scotland. The SHFNF passed on their grateful thanks to the CPG.

- **Actions from session with Cabinet Secretary for Health & Wellbeing**

- **Smoking in cars legislation;** progressing well and next update due in Spring 2014
- **Caring Together;** deferred for update at December meeting
- **Letter on standardisation packaging of Tobacco;** events at a UK level overtook this action and Scottish Government have now given their commitment to seeing this implemented in the next parliamentary year
- **Stroke Charter;** Letter sent 2nd July 2013 reply from Cab Sec 5th August 2013 to express interest in viewing final version of the Charter and potential interest in attending event
- **HEAT Target;** letter sent to Cab Sec in September 2013 and reply awaited

- **Sub-Group Update**

Kim Hartley [KH] tabled a paper on the final draft Stroke Charter and an outline plan for a launch event in December. KH highlighted the key organisations (voluntary and statutory) who had given their support to the Charter and sought the endorsement of the CPG to finalise the work and launch the Charter. There is also a website under development which will host the Charter and additional information, including references.

Members of the group congratulated the Sub-Group on all the hard work that had gone into the development of the Charter. Some ideas to strengthen the document were shared and to be discussed by the sub-group and the draft Charter was endorsed. HE emphasised that the Charter was designed to be an 'aspirational document'.

4. Presentations

Campaign & Petition for ACHD: Dr Liza Morton, Scottish Campaign Manager, The Somerville Foundation
Dr Liza Morton shared her perspective on the issues facing Adult Congenital Heart Disease patients in her role with The Somerville Foundation. Liza was born with complete congenital heart block and fitted with her first pacemaker at 11 days old at Yorkhill Hospital (a world first at the time). She has been in and out of hospital her entire life requiring many surgeries, including those to fit ten pacemakers and open heart surgery to fix a hole in her heart. Liza talked through both the good and bad aspects of her experience and the 'fears' shared by all living with ACHD conditions; she asked the members to consider how it felt to be entirely dependent on a man-made and fallible device.

As well as her personal experience, Liza highlighted the 9 Points of The Somerville Foundation's vision and circulated copies of the document to members. Liza was also instrumental in submitting a petition to the Scottish Parliament and giving evidence to the Committee in November 2012; the petition is currently due for review again in 2014. Liza concluded by emphasising that Scotland was uniquely placed to address the challenges faced by those living with ACHD (1 in 145) births and urged that further progress be made in setting standards for care.

Patient Survey and Conference consultation results - Dr Hamish Walker [HW], Clinical Lead, Scottish Congenital Cardiac Network

Dr Hamish Walker is the Director of the Scottish Congenital Cardiac Service and Adult Clinical Lead for the Scottish Congenital Cardiac Network and he provides cardiac MRI imaging for ACHD patients under the care of the National Service at the Golden Jubilee National Hospital.

HW highlighted that Congenital Heart Disease is the commonest birth defect and that now up to 85% of babies survive into adulthood, requiring ongoing treatment throughout their lives; the numbers are increasing. HW shared the stages of formation for the new Scottish Congenital Cardiac Network [SCCN] and the importance of it involving all key partners and building on existing good work in Scotland.

HW went on to present the initial scoping results collated for the inaugural SCCN meeting in March 2013. The survey contained searching questions and one aspect was how 'safe' ADCH patients felt when they needed care. The survey highlighted particular challenges for Primary Care in improving care for these patients and HW highlighted that clinicians' responses highlighted 'shared care' as a key area of concern. HW finished by outlining the priorities for SCCN work; establishing links and local clinics, a newsletter and the first Steering Group meeting is scheduled for the 23rd September 2013.

5. Discussion

HE extended a special welcome to those directly affected by Adult Congenital Heart Disease [ACHD] in the audience; both those living with congenital conditions and those who have cared for a child with a congenital condition. The barriers to accessing care were discussed with particular reference to the West of Scotland. It was acknowledged that the number of ACHD patients is a success story as people are living into adulthood with these conditions. The group discussed the potential of a Charter for ACHD patients, in the way that the subgroup had produced the Stroke Charter and it was agreed to come back to this for consideration in the future.

There was discussion on the availability of out of hours care for ACDH and that when available, specialist care could be 'amazing' but hard to access out of office hours. LM updated that the Petition that she had presented was currently on hold for review in 2014 once the SCCN was established. John Richardson [JR] Director of The Somerville Foundation commented that he was optimistic about positive change in Scotland and emphasised the need for partnership working on ACHD.

Anne Reoch [AR] speaking on behalf of NHS 24, reminded the group that Scotland had many opportunities through the Community Health Index [CHI] number, allowing provision of coordinated care, the Emergency Care Summary (ECS) has now developed into the Key Information Summary [KIS], which also allows patients to add information via their GP. (Post meeting note: Following this meeting a trial of KIS will be launched at the beginning of 2014 for the congenital cardiac patient group. This is a collaboration between eHealth, SCCN, SCTT/NHS24 and Primary Care.)

Nicki Walker [NW] highlighted that Scotland currently only has 2 Specialist Cardiologists for ACHD. The discussion concluded with all acknowledging that timely access to specialist care is essential for those with ACHD. HE thanked both speakers for their excellent presentations.

Action:

LM to send HE information for potential Parliamentary Questions on the provision of out of hours care for ACHD

CPG to send letter to the Cab Sec for Health to clarify the arrangements for out of hours care in ACHD, potential for a guidance system for GPs to access (e.g. like RefHelp in Edinburgh Practices), whether a Standards Document could be developed to compel generalists to seek specialist help in ACHD cases.

CPG to keep in touch with situation with ACHD care and feature an update at future meeting.

6. AOCB

CPG on Chronic Pain

HE shared a request from the CPG on Chronic Pain to circulate a survey link to the members by email. The group were in agreement and the Secretariat will circulate.

7. Date of next 2013 meeting & 2014 dates:

- **“Palliative Care for those with Heart and Stroke conditions”: Wednesday 4th December 2013, Committee Room 5 (Joint Meeting with the CPG on Palliative Care)**
- Wednesday 12th March 2014
- Wednesday 11th June 2014
- Wednesday 17th September 2014
- Wednesday 3rd December 2014

Non-MSP attendance

Title	Forename	Surname	Organisation
Ms	Sheena	Borthwick	NHS Lothian
Ms	Valerie	Breck	Visibility
Mrs	Jan	Buncle	Chest Heart & Stroke Scotland
Ms	Marjory	Burns	BHF Scotland
Dr	Geoff	Dobson	RCGPs
Ms	Anna	Gardiner	Scottish Congenital Cardiac Network
Ms	Jane	Gibson	Rebecca's Rainbow Heart Ebstein's Anomaly Trust
Ms	Maura	Gillespie	BHF
Ms	Kim	Hartley	Royal College of Speech & Language Therapists
Mrs	Laura	Hastings	Chest Heart & Stroke Scotland
Mrs	Mary	Hemphill	ACHD Patient
Ms	Vicki	Hendry	The Somerville Foundation
Ms	Suzi	Hutchinson	Little Hearts Matter
Ms	Jane	Irvine	ACHD Carer
Mr	Chris	Macnamee	Patient Representative/Voices Scotland Volunteer
Ms	Brin	Maki	Scottish Congenital Cardiac Network
Mr	Ben	McKendrick	BHF Scotland
Ms	Jacqueline	McShane	Medvivo
Ms	Gill	Mitan	Bravehearts Patient's Group
Ms	Elsbeth	Molony	The Stroke Association
Dr	Liza	Morton	The Somerville Foundation
Dr	Walayat	Muhammad	NHS Lothian
Mr	Chris	Myers	NHS National Services
Dr	David	Northridge	NHS Lothian
Ms	Linda	O'Neill	BHF
Mr	Robert	Paton	GCRA
Ms	Elizabeth	Paul	ACHD Carer (Dr Morton's mother)
Mr	Findlay	Paul	ACHD Carer (Dr Morton's father)
Miss	Louise	Peardon	Chest Heart & Stroke Scotland
Mrs	Carol	Reid	Bravehearts Patient's Group
Mr	Ian	Reid	Bravehearts Patient's Group
Ms	Helen	Reilly	BMA Scotland Public Affairs Office
Ms	Anne	Reoch	Scottish Centre for Telehealth & Telecare (SCTT) / NHS 24
Mr	Jamie	Rice	Boehringer-Ingelheim
Mr	John	Richardson	The Somerville Foundation
Ms	Janice	Shields	ACHD Carer
Ms	Laura	Shields	ACHD Patient
Mr	Eric	Sinclair	The Stroke Association
Mr	Roderick	Skinner	The Somerville Foundation
Mr	Mark	Smith	NHS Lothian
Mr	Gordon	Snedden	Angus Cardiac Group
Ms	Lorna	Stevenson	Chest Heart & Stroke Scotland
Prof	Allan	Struthers	University of Dundee/Ninewells Hospital
Dr	Muhammad	Walayat	SCCN

Mrs	Carol	Walford	
Dr	Hamish	Walker	Scottish Congenital Cardiac Network
Dr	Niki	Walker	Scottish Adult Congenital Cardiac Service
Ms	Justine	Westwood	NHS 24