

**PE1446/E**

20<sup>th</sup> December 2012

Andrew Howlett  
Assistant Clerk to the Public Petitions Committee  
Scottish Parliament  
EDINBURGH  
EH99 1SP

Dear Mr Howlett

Re: PE01446: Scottish Standards for the Care of Adult Congenital Heart Patients

We would like the Committee to note our support of public petition PE01446, calling on the Scottish Parliament to urge the Scottish Government to mandate National Standards for the care of Adult Congenital Heart Patients and to adequately resource the Scottish Adult Congenital Cardiac Service (SACCS).

Bravehearts supports the need for the development of standards for the commissioning of services for people who live with Adult Congenital Heart Disease in Scotland. Congenital heart disease covers a range of heart conditions resulting from an abnormality of the heart structure or function that is present at birth. With the population of Scotland approximately 5.3 million it is estimated that around 16000 adults in Scotland now live with adult congenital heart disease. These figures will continue to grow as approximately 160 teenager's transition to the adult service at the Golden Jubilee alone per year. Whilst many of these individuals will not require the support of a specialist service, it is clear that the service will continue to grow at a rapid rate as access to the service continues to develop as well as increased awareness raised by the clinicians of the service and the patient groups.

There is believed to be a significant numbers of adults living with congenital heart disease in Scotland who have been lost to follow up, if the service was adequately resourced work could be undertaken to try and locate the missing adults, at present this is not possible as the SACCS service does not have the capacity to treat/manage the estimated 8000 missing adults.

Until the development of SACCS, the care of patients with adult congenital heart disease in Scotland was largely a local and regional issue. Care was fragmented with some non-specialist clinicians who had an interest in CHD managing those patients who actually required specialist care. The formation of the SACCS service led to those services being supported and having access to specialist advice and management. Due to inadequate resourcing of the SACCS service currently SACCS clinicians currently do not provide support for local or regional outreach clinics. A strategy for delivery of ACHD care in the future in Scotland [currently with the

Scottish Government for approval] will be dependent upon active involvement in local services, therefore to allow for this to occur the service would need appropriate additional resources.

There are now more adults living with CHD than children for the first time ever largely due to advances in ground-breaking surgery and medication. These individuals are first generation adults whose lives are risked due to the lack of standards and provision to treat them adequately as previously many would have not lived to adulthood.

Bravehearts are concerned as we have been for some time that many of the individuals affected by these conditions have to “battle their way” through the medical system in order to receive the care and support they need to best manage their condition. We welcome the suggestion in the content of the petition that national standards for the care of Adult Congenital Heart Patients could be developed from “A commissioning guide for services for young people and Grown Ups with Congenital Heart Disease”, published by the Department for Health in 2006 and adapted to suit Scottish circumstances. The English standards for example cover support for patients as they move to the adult service, availability of specialists in out-reach clinics and protocols for General Practitioners when dealing with patients with CHD.

Our Patient Association would also ask the Committee to note specific concerns expressed by the petitioner about a lack of understanding among health professionals and a lack of available A&E provision, this is an issue members raise with us frequently. The issues around medical care and lack of standards make it intolerable and put emotional strain on individuals who have had to battle since birth to live to have a good quality of life.

The latest annual report from Scottish Adult Congenital Cardiac Services [2011/2012] reports risk and oversubscription in many categories such as the Obstetric Cardiac Service to give an example. Our members are active individuals who work and contribute a significant amount to society; they deserve to do so with peace of mind and provision of services to assist them in remaining well so they may continue to pursue independent successful lives in their community.

Bravehearts has been involved in working alongside SACCS and the National Service Division with regards to drawing up protocols for the service as well as other matters but have grown increasingly frustrated by NSD's stance that they will wait on the English standards implementation – six years on Scotland are still waiting and now NSD wish to wait on the review of the English Standards before looking at implementation again, we believe Scottish patients deserve better especially since the health in Scotland is a devolved issue.

We have previously written as individuals to MSP's and the Health Minister for assistance with this issue and are repeatedly told NSD are dealing with the issue but this is clearly not the case. We support the Petitioner in this action and hope that our concerns listed above as taken onboard when the petition is discussed by your committee. We are happy to provide further information to your committee either in person or in writing to assist you in considering this important issue.

Yours sincerely

**Gill Mitan**

**Chairperson on behalf of Bravehearts Patients Association**

### **Appendix**

Bravehearts is the adult branch of the Scottish Association for the Children for Heart Disorders and is run by adults with adult congenital heart disease for individuals affected by CHD.

An example of what we do:-

- Share information and arrange communication forums for congenital heart patients
- Work with all other congenital heart charities and patient groups in the UK and abroad
- Promote and support the work of quality research
- Work with all health professionals in collaborative encouragement

### **Links for Further Reading**

<http://www.heraldscotland.com/news/health/heart-defect-survivors-in-fight-for-help.18876014>

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4134608](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134608)

[http://heart.bmj.com/content/early/2012/12/19/heartjnl-2012-302831.full?g=widget\\_default](http://heart.bmj.com/content/early/2012/12/19/heartjnl-2012-302831.full?g=widget_default)

The Strategy for ACHD Care in Scotland or the latest annual report for the service have not as yet been available online so I am unable to provide the link here.