

PE1446/F

21st 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].

We believe that the points raised by the petitioner are very valid. Adults born with a heart defect have the right to receive the same equitable care that children receive in paediatric care. Given the evidence that there are now more adults than children living with congenital heart disease it is perhaps timely that this issue has been raised. It is important to our association that the issues raised are resolved timeously as the numbers of those transitioning from paediatric care at Yorkhill to the Adult services continues to grow [current estimates suggest that approximately 165 teenagers transition from the service at Yorkhill to the SACCS service alone each year, this figure does not include those who transition to adult cardiac services in other parts of Scotland].

The petition seeks more adequate resourcing of the SACCS service and this is almost certainly needed as the service is already overstretched based on the most recent annual report. There is believed to be a significant number of adults living with CHD in Scotland who have been lost to follow up due to changes in guidance since the 1980's, if the service was adequately resourced work could begin 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.

Our association also supports the need for development of national standards for the care of adults with congenital heart disease. The 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:-

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4134696.pdf. Standards are required and should not be delayed until the

outcome of the review of provision of CHD services is complete in England & Wales in 2014. The standards would help to avoid the difficulties many adults with these conditions face in

accessing appropriate support at the times of ill health when attending a GP or A&E services for example.

We hope that the Petitions Committee can pursue this important matter with the Scottish Government and are pleased to have been given the opportunity to state our opinion on this issue.

Yours sincerely

Scottish Association for Children with Heart Disorders