



PE1446/A

19 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).

Congenital heart disease describes a range of heart conditions resulting from an abnormality of the heart structure or function that is present at birth (Department of Health, 2006). Scottish Government statistics suggest that around 15,600 adults in Scotland live with adult congenital health disease (Scottish Government, 2009), though many of these people are unknown to the health and social care system.

The ALLIANCE supports the views expressed in the petition, in particular the need for the development of standards for the commissioning of services for people who live with Congenital Heart Disease in Scotland. The ALLIANCE believes that a person-centred approach that considers the psychosocial impact of living with a life threatening condition should be advocated to meet the needs of this growing population. The ALLIANCE would also urge the Committee to note particular concerns expressed by the petitioner about a lack of understanding among health professionals and a lack of available A&E provision.

Evidence contained with the latest annual report from Scottish Adult Congenital Cardiac Services reports risk and oversubscription in many categories and the ALLIANCE is concerned that many of these people still feel they have to “fight their

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way” through the medical system in order to receive the support they need to best manage their condition.

The ALLIANCE welcomes 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.

Yours sincerely

Ian Welsh
Chief Executive, Health and Social Care Alliance Scotland

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