



The Scottish Parliament  
Pàrlamaid na h-Alba

**PUBLIC PETITION NO.**

**PE01446**

### **Name of petitioner**

Dr Liza Morton on behalf of Scottish Adult Congenital Heart Patients

### **Petition title**

Scottish Standards for the Care of Adult Congenital Heart Patients

### **Petition summary**

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).

### **Action taken to resolve issues of concern before submitting the petition**

I have written to Nicola Sturgeon, MSP on numerous occasions over the last few years as have many other ACHD patients. Recently, Michael Moore, Secretary of State for Scotland has also written to Nicola Sturgeon, MSP on my behalf. Any responses have been unsatisfactory and usually indirect.

More recently, I have been working with the NSD (National Service Division) following a complaint I made about my care last year. After meeting with them to discuss my concerns we formed a working group and have met monthly to review progress. However, progress is slow and seems to be hindered by a lack of political interest and drive. I have also highlighted my concerns with the Long Term Conditions Alliance (LTCAS) and I am a member of their Patient Involvement Network to try and raise awareness about ACHD. I also work as a patient volunteer for the Somerville Foundation (formerly known as Grown Up Congenital Heart Association - GUCH PA). I have raised my concerns with Bravehearts who support fully my submission of this petition.

Prior to the development of the Scottish Parliament and devolution of health I wrote to the Department of Health when I first left paediatric care 16 years ago, many MPs and the then Prime Minister, Tony Blair.

### **Petition background information**

Congenital heart disease is the most common birth defect affecting 8 per 1000 live births. In Scotland this equates to 450 to 600 children being born each year with this condition. It is estimated that there are around 15,600 adults living in Scotland with

adult congenital heart disease (ACHD) (Scottish Government, 2009). Over 90 per cent of infants born with heart defects are now reaching adulthood (Kovacs et al., 2009) whereas only 20 per cent survived in the 1940s (Warnes et al., 2001). This demonstrates the success of medical advances and intervention for congenital heart disease. Indeed, we benefit from world class Cardiologists and Surgeons in Scotland.

The work that they do can add not just a few years to the end of a patient's life but can gift a whole life to a baby who would otherwise have died in infancy. However, this life is not won easily for either party. Often, care is required to maintain health for the rest of this patient's life. Our Cardiologists cannot be expected to do their work without adequate resources. Patients should not be expected to fight both their condition and the medical system. Both sides of this team need standards to support their unique journey.

Consequently, for the first time in history there are now more adults than children living with this condition. Adults trying to live as normal a life as possible, many in employment with young families. There is no cure for congenital heart disease. We live with this condition from birth to death encountering many potential difficulties along this journey including surgeries, limited physical activity, hospital stays, discrimination, lack of awareness, living with medical devices, to name a few. Further, for some, a heart transplant may be required and life expectancy may be shortened. Some are unable to have a family. Living with a heart condition from birth also presents many psychosocial challenges (Morton, 2011).

Recently, we have benefited from the designation of the Scottish Adult Congenital Cardiac Service (SACCs), a specialist national centre, run by a dedicated and excellent team of pioneers. For the ACHD population there is a wide variation in the complexity of our heart conditions. Some cases are minor and do not require treatment. However, it is estimated that in Scotland over 3000 patients do need regular contact with the specialist SACC service and a further 7000-8000 patients require review (SACCs Annual Review, 2011-2012). The contemporary approach in the care of ACHD patients is to maintain cardiac function through a preventative approach rather than "fire fighting".

Indeed, this offers a more efficient use of NHS resources. Although the SACCs service is run by a committed and forward thinking team it is under resourced for the growing population it is required to care for, potentially compromising care. Further, the service does not include psychological support, social work input, physiotherapy or any other holistic care. Nor does it have a funded pacing service or A&E.

In 2006, the DoH produced "A commissioning guide for services for young people and Grown Ups with Congenital Heart Disease (GUCh)" stating standards that were adopted in England and Wales. Currently, these standards and ACHD services in England and Wales are undergoing a further review. Yet, more than five years down the line Scottish ACHD patients are still waiting on the development of national standards. This lack of standards for our care presents us with difficulties. Particularly with local care. Many of us have experienced potentially life threatening problems at A&E and have encountered difficulties with GPs, obstetric care, dentistry, non specialist cardiologists and with other allied healthcare professionals.

Having navigated the many challenges of a childhood lived with heart disease, as adults, we are asking the Scottish Government to continue to support us on this difficult journey. Living with a heart condition from birth is difficult enough without having to fight our way through the medical system. We need standards for our care to ensure our safety, equity of access and quality of life.

Please support us on this by mandating standards for our care. These could be easily developed from "A commissioning guide for services for young people and Grown Ups with Congenital Heart Disease (GUCh)". (DoH, 2006).

### Unique web address

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/AdultCongenitalHeartScottishStand>

## Related information for petition

NHS Commissioning Guide:

<http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance>

SACCs Service: <http://www.nsd.scot.nhs.uk/services/specserv/saccs.html>

Psychosocial Impact of ACHD: [http://dcop.bps.org.uk/publications-database\\$.cfm?&ResultsType=Abstracts&ResultSet\\_ID=238&FormDisplayMode=view&frmShowSelected=true&](http://dcop.bps.org.uk/publications-database$.cfm?&ResultsType=Abstracts&ResultSet_ID=238&FormDisplayMode=view&frmShowSelected=true&)

GUCH PA/Somerville Foundation: <http://www.guch.org.uk/>

Bravehearts: <http://www.youngheart.info/bravehearts/index.htm>

Other Relevant Articles can be downloaded from here:

[http://www.linkedin.com/profile/edit?trk=hb\\_tab\\_pro\\_top](http://www.linkedin.com/profile/edit?trk=hb_tab_pro_top) (from BOX at bottom of profile page)

Other relevant links:

<http://thesfblog.wordpress.com/2012/06/25/the-good-patient/>

<http://thesfblog.wordpress.com/2012/05/24/coming-out-as-a-guch/>

[http://www.guch.org.uk/experiences/gnpdfs/GUCH\\_News\\_Issue\\_68.pdf](http://www.guch.org.uk/experiences/gnpdfs/GUCH_News_Issue_68.pdf) (see Page 14)

**Do you wish your petition to be hosted on the Parliament's website to collect signatures online?**

YES

**How many signatures have you collected so far?**

0

**Closing date for collecting signatures online**

19 / 10 / 2012

**Comments to stimulate online discussion**

Despite the DoH developing standards for the care of Adult Congenital Heart Patients in 2006, and many ACHD patients reaching adulthood a generation ago, Scottish patients still do not have national standards for their care.

Without Standards there are no guidelines for the care of ACHD patients. This presents risks particularly regarding the care of ACHD patients by non-specialist cardiologists.

Further, this means there are no standards to guide the care of ACHD patients for GPs, when they present to A&E or other to health professionals.

This also means that consistency and equity of care cannot be standardised.

Without standards how can gaps in services and between the current level of care and that required be measured and monitored?

How can patients ensure that they are receiving the care to which they are entitled without standards? How can they inform themselves, and local care providers, about their care?

Without standards many patients are left feeling uncertain about their care and unsafe.

A growing number of CHD patients are leaving paediatric care each year and will also need to be supported as adults.

A lack of adequate resources and standards leave clinicians "fire fighting" rather than

being able to provide adequate or preventative care. This is not an efficient use of NHS resources. The NHS is left to pay for its "mistakes". Further, this economic burden is even greater if loss of earnings and sick pay are taken into account.

Is it ethical to provide world class care to save a baby's life, with palliative rather than preventative treatment, if this care is not extended to the rest of that person's life?