Cross Party Group on Heart and Circulatory Diseases

Wednesday 29th March, 6-7.30pm

Via Microsoft Teams

Minutes

MSP attendees

Alexander Stewart MSP (Chair)

Karen Adam MSP

Invited attendees

Nichola Dougan

Scarlett Dougan

Dr Lorna Swan (NHS Golden Jubilee)

Lesley Hill

Rodger Hill

Caroline Coats (NHS Greater Glasgow and Clyde)

Non-MSP attendees

Emma Young (British Heart Foundation Scotland)

Mike Parker (Office of Alexander Stewart MSP)

Jonathan Roden (British Heart Foundation Scotland)

Prof Lis Neubeck (Edinburgh Napier University)

Mary Galbraith

Joel Rose (Cardiomyopathy UK)

John Dean (NHS Grampian)

Kym Kestell (British Heart Foundation Scotland)

Lynn Stewart

Maggie Simpson

Dr Ross McGeoch

Steve Cox

Sophie Bridger (Chest, Heart and Stroke Scotland)

Welcome and apologies

Alexander Stewart MSP welcomed members to the meeting. Minutes from the last meeting held on Wednesday 8th of February 2023, were agreed and are available on the Scottish Parliament website.

Apologies: Colin Smyth MSP.

AGM

Re-election of office bearers took place.

Alexander Stewart MSP, Karen Adam MSP and Colin Smyth MSP

Proposer: Jonathan Roden

Seconder: Prof Lis Neubeck

Secretariat: British Heart Foundation Scotland

Proposer: Alexander Stewart MSP

Seconder: Dr Ross McGeoch

Topic discussion: Heart disease and young people

Nichola and Scarlett Dougan, *Scarlett lives with a congenital heart condition, called hypoplastic right heart syndrome. Scarlett and her mum, Nichola, discussed Scarlett's experience of the condition. Scarlett was not diagnosed with this condition until she was 4 and ½ months old.*

Nichola discussed that following advice from a family friend studying paediatrics who noticed Scarlett looked poorly, Nichola took Scarlett to hospital. She was told Scarlett was a healthy baby, that Nichola was an anxious mum and not to pick Scarlett up as often.

Nichola asked for saturations to be checked following advice from the friend, and the results showed 36% oxygen in Scarlett's body; she was then rushed into resuscitation.

Scarlett was in intensive care that evening, with planned open-heart surgery the following day. However, the decision was made to wait until Scarlett was stronger.

Scarlett has now developed an understanding of her condition and realises the adaptations required in her life. She is now going to be moving to secondary school.

Scarlett spoke about how most of the time she feels well but notices some things at school that remind her of her heart condition such as walking upstairs or carrying her cello. Scarlett has been swimming with her class, enjoys PE, and dancing, but can get very tired when

doing this more than the other children. Scarlett is aware of how lucky she is doing these activities.

Nichola worries for Scarlett moving from child health services to adult, and questions will it be more clinical and less friendly.

Nichola noted how Scarlett will need a heart transplant at some point in her life.

Nichola and Scarlett with their family fundraise for the BHF and Glasgow Children's Charity each year by holding Scarlett's Ball and hope to contribute to lifesaving research.

Dr Lorna Swan, *Consultant Cardiologist, the Scottish Adult Congenital Cardiac Service, NHS Golden Jubilee*

Dr Swan highlighted that congenital heart conditions are present in around 0.8% births. Noting that 9 out of 10 children born with a heart defect now survive into adulthood thanks to medical advances.

- For some patients that does mean ongoing health issues and lifelong conditions which need lifelong medical care, for example: need for repeated operations and interventions, pregnancy complications and need for transplantation.

Care for young people: children are looked after by the paediatric cardiology team until 16. Around age 14, parallel process of transition services, which is mainly nurse led to bridge the gap between paediatric team and adult services. Dr Swan notes this is often a time of anxiety for families.

Baby R example**:** born at 35 weeks, prenatal diagnosis, x3 major cardiac surgeries before first year of life with first 7 months spent in hospital. Annual follow up reviews including repeat invasive tests. Diagnosed with ADHD which many patients have. Experiences challenges at school, e.g., not being involved in PE and bullying. Issues with body image due to scars, and some medical related anxiety. Although feeling normal and thinking about education, career choices and maybe family planning.

Dr Swan discussed what success looks like when looking after young people including: keeping young people engaged in care, tailoring their care, and improving quality of life/empowering individuals.

It's common to lose patients to follow up when they become teenagers, this is not true for sickest patients as we see them regularly and don't lose them in the system. Those with moderate or significant complexities will often have gaps in medical care, particularly teenagers don't want to come to clinic, or have moved house and not changed on systems. Patients with congenital heart disease who are looked after by a specialist centre, will live longer than those who are not. This presents a significant issue to morbidity and mortality.

Tailoring care for young people: transition clinics and for example by video rather than face-to-face. Transition days for children and family to meet the team.

- Trying to make the young person more independent and responsible for making decisions considering their health. Will be done through patient education, psychological support, parental education, and social interaction. Doing this will keep engagement with patients and not have gaps in care.
- Teenagers do not read leaflets, therefore, social media, and online resources much more appropriate. Peer to peer support and third sector charities important to provide specific groups.

Improving quality of life: illness perception (empowering patients, developing skills, coping strategies, education, and opportunity).

We know what great care looks like and the benefits.

- Could do better: limited access (one specialised psychologist for entire country) no effective database to track journey from child to adult, regional variation in transition services, e.g., those living in West of Scotland likely have better experience.

Dr Caroline Coats, *Consultant Cardiologist, NHS Greater Glasgow and Clyde*

- Inherited cardiac conditions: genetic basis between cardiomyopathies and channelopathies.
- Out of hospital cardiac arrest: in young people consider structural causes, such as coronary heart disease, cardiomyopathies, myocarditis, and aortic dissection.
- OCHA Strategy: focus on each end of cardiac arrest chain, both in readiness - ability to deliver CPR quickly and effectively, and then aftercare, not only the individual but community that has been affected.
- Most common inherited condition in Scotland is hypertrophic cardiomyopathy. Genetic testing for this, illustrates different volume of testing in different places.
- Clinical care for hypertrophic cardiomyopathy: patients aware this condition may lead to cardiac arrest, heart failure or stroke. Patients require good clinical care from childhood to older age.
- Fortunate to receive funding in Scotland through BHF and Miles Frost fund, to improve cascade testing - genetic testing in families. Issue of data, value of national database particularly linking family records.
- Genetics provides opportunity to intervene early:
- Importance of the patient journey: example, patient had cardiac arrest in swimming pool; his wife 6 months pregnant and baby was ultimately found to carry same genetic. Listed over 100 health care professionals he interacted with from the cardiac arrest to diagnosis in a year. These conditions cross broad spectrum of the health service.
- Key challenge in delivering healthcare in this area is the multi-disciplinary nature.

Lesley and Rodger Hill. *Lesley and Rodger spoke to the group about their experience of losing their son David and discussed raising awareness of undiagnosed heart conditions.*

Rodger spoke about David, noting he was born in 1991, was fit, enjoyed sport particularly rugby and working in the Parliament.

David was a member of the Scottish Parliament rugby team, and was playing ruby in Ireland, when he turned to his colleague and said he had a bit of a headache. He then knelt and laid down. Medics were present and started providing CPR to David, with the defibrillator to hand.

Rodger discussed how earth shattering the phone call from the hospital was saying David had passed away.

Rodger highlighted how after his death, David was looked after extremely well.

Rodger noted that they reached out to Cardiac Risk in the Young (CRY) and received support through counselling to deal with the suddenness of losing David, and how to prepare for the future. Rodger noted Lesley and himself were given expert advice and guidance, and help reviewing David's post-mortem. During post-mortem report they heard the word channelopathy for first time and that this could be the electrical cause for David's death.

They have been involved with fundraising and raising awareness of sudden cardiac death, an example was a recent memorial match between Scottish and Irish Parliaments rugby teams.

Since beginning fundraising in November, 20,000 people screened in their home area. Rodger and Lesley would like to see change, noting at least 12 young people suffer a sudden cardiac death every week in the UK caused by an undiagnosed cardiac condition. Discussion was had of CRY's national strategy for the prevention of young sudden cardiac death.

<u>Question and discussion</u>

Q.1 Lesley Hill: what can we do to help? Might be in a slightly unique position due to David's workplace – having the ears of some politicians. And the support of CRY's research teams. We want to do things that make a difference.

Dr Caroline Coats: key thing as inherited conditions and congenital heart condition specialists, we often feel left in the corner compared to much larger body of conditions such as high blood pressure, heart attacks and heart failure. We are dealing with a young proportion of society who possibly have a lot to lose, not to negate other conditions, but awareness raising of these conditions is important.

Jonathan Roden: as part of HDAP, the health and social care alliance run a lived experience panel alongside BHF and CHSS engaged in a lot of work going on behind HDAP - good forum to see how a lot of that work is implemented.

Q.2 Mary Galbraith: what research/pathways are there for lesser-known congenital conditions e.g., myocardial bridging (which is often thought as benign – but is found in up to 30% of patients with hypertrophic cardiomyopathy) but is possible responsible for range of other chest pain conditions e.g., coronary spasms?

Dr Caroline Coats: research makes a big difference to a huge number of people. Specifically myocardial bridging, not aware of specific research in Scotland, but signed up to European SCAD registry – need to work across regions and internationally. Involved in driving forward research in the field of inherited cardiac conditions – make Scotland attractive to carry out research.

Prof Lis Neubeck: raised with CSO that we have an under resourced cardiac research network in Scotland, only one day a week and one project manager, disproportionate to number of studies run – currently around 155 clinical trials in Scotland. Must readdress balance of funding for research networks to achieve better cardiovascular research in Scotland.

Dr Ross McGeoch: Cardiovascular disease generally in Scotland feels underrepresented.