

Newsletter



Updates from
your CHD Network

Inside this edition

Clinical Director's Introduction...2

Clinical innovation: award winners...3

Nursing updates...4

Developing a nurse specialist role in
peripheral centres ...5

Education and training...6

A holistic psychological approach...7

Echocardiology training...7

Youth space...8

Welcome and staff changes...9

Graham Stuart retires...10

Clinical guidelines...11

Network updates...12

Staff photo competition...13

Lillian's patient story...14

Useful contacts...16





Introduction from our Clinical Director Dr Stephanie Curtis

Welcome to the New Year 2025 edition of the South Wales and South West Congenital Heart Disease Network newsletter!

As the weather gets cold and wards get busy with winter viruses, it is time to reflect on 2024. The year has flown by and our teams across the Network have been busy as always providing the best care they possibly can to our patients and their families. As a Network Team, we spent a large part of the year conducting Self-Assessment visits with our Level 3 Centres in the South West of England. These were very productive, and we very much enjoyed meeting with the teams, working together to try to improve services for our patients. We did end up with an enormous to-do list that we are slowly chipping away at!

Congratulations to our ACHD interventional team who are really pushing the boundaries of what is possible in some of our most complex patients to avoid high-risk open heart surgery. To win a prize at CSI Frankfurt is the cardiological equivalent of an Oscar (!) and very impressive indeed.

One of the strengths of our Network is patient and parent engagement. I loved the work that Xander and the Youth at Heart team did with patients (including those with learning disabilities and neuro diversity) to produce a warm and welcoming waiting area in the Bristol Heart Institute. We are grateful to charities for funding projects such as these that make a big difference to the patient experience.

There has been a lot of change in staffing across the Network and big changes in clinical leadership in cardiology in both Cardiff and Wales. Both Dr Tim Murphy and Dr Patricia Caldas have significant leadership and management experience and will, I am sure, bring many excellent changes to the Children's Cardiac Services in Bristol. Mr Shafi Mussa has always been a great champion of the Network, and we look forward to working more formally with him as Congenital Surgical Lead at University Hospitals Bristol and Weston. We are very sad to lose Dr Jennifer Holman after a career of dedication to paediatrics and cardiology in Gloucester and we wish her well in her retirement. Professor Graham Stuart needs no introduction, and we have dedicated a whole page to him in this newsletter to try to convey his importance in the development of the ACHD service in Bristol. The Bristol Heart Institute and Children's Hospital in Bristol will not be the same without him.

Finally, once again, I was unable to compete with the excellent entries for the photographic competition! I hope you enjoy the fruits of the talented photographers in our Network on page 13. I wish you all a happy and healthy 2025 and hope you enjoy reading this latest edition of our Newsletter.

Dr Stephanie Curtis
Clinical Director, South Wales and South West CHD Network

Front cover photo credit: Emma Mugford, Medical Secretary, South Wales

Your South Wales and the South West Congenital Heart Disease Network is here to support CHD patients of all ages throughout their cardiac journey, as well as their families/carers and the staff who are involved in CHD care across your Network.

Your Network connects all of the hospitals, services, staff, and patient/family representatives from across South Wales and the South West of England. Together we aim to deliver the highest quality care and experience for our patients.

The Network is also part of a national group of congenital heart Networks.

[Network Team Key Contacts](#)

Clinical Director: Dr Stephanie Curtis
Stephanie.Curtis@uhbw.nhs.uk

Lead Nurse: Sheena Vernon
Sheena.Vernon@uhbw.nhs.uk

Lead Nurse: Becky Lambert
Becky.Lambert@uhbw.nhs.uk

Network Manager: Michelle Jarvis
Michelle.Jarvis@uhbw.nhs.uk

Support Manager: Rachel Burrows
Rachel.Burrows2@uhbw.nhs.uk



Clinical Innovation: Award Winners

Transcatheter Edge To Edge Repair In CHD

An alternative to open heart surgery for repairing mitral and tricuspid valves

By Dr Stephanie Connaire, Cardiology Registrar ACHD, Cardiff (previously at the Bristol Heart Institute)

A number of Adult CHD team members from the Network travelled to Germany to attend CSI Frankfurt 2024. The yearly conference is focussed on catheter interventions in congenital, structural and valvular heart disease with presentations from leading experts around the world and updates on the latest trials and technologies.

ACHD Fellows Dr Stephanie Connaire, Dr Anindya Mukherjee and Dr Alberto Fuensidala, had a collection of abstracts accepted. They represented the South Wales and South West CHD Network by presenting their work in the E-poster and Cath Lab Café sessions.

Dr Stephanie Connaire was presented with a Best Poster Award for her poster 'Transcatheter-edge-to-edge repair in congenital heart disease: a single centre case series.' This included the first five procedures in patients with congenital heart disease in the Bristol Heart Institute, discussing our experience in Bristol and the increasing use of this technology in our patient population.

To find out more: <https://app.csi-congress.org/p/Dt2mJPnXincpSjAFj/s/oDHgCx32SB9Ry94Wj>



Image: Dr Stephanie Connaire receiving a Best Poster Award at CSI Frankfurt 2024.

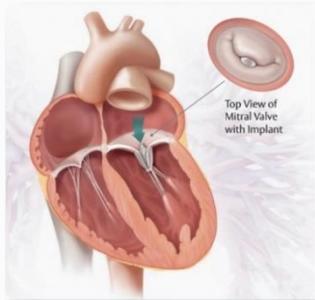


Image depicting tricuspid valve TEER with single 'clip' on the right-sided tricuspid valve. www.edwards.com

A little background on the procedure: Transcatheter edge-to-edge repair

Transcatheter edge-to-edge repair (TEER) is a minimally invasive procedure used to repair leaking heart valves without the need for open heart surgery. It involves placing a 'clip' on the leaking heart valve to reduce the leak and therefore improve symptoms. It is performed under general anaesthetic in the cardiac catheterisation lab with the guidance of X-rays and ultrasound imaging.

A small incision is made to access the femoral vein in the groin. The catheter is passed up through this vessel and up to the right side of the heart. For procedures on the left sided (mitral) valve, specialised equipment is used to make a small hole in the wall dividing the heart chambers (atrial septum) allowing the catheter and equipment to pass into the left side of the heart. The 'clip' is then passed through the catheter and carefully positioned on the valve according to the exact site of the leak. Sometimes more than one 'clip' is required to sufficiently reduce the leak.

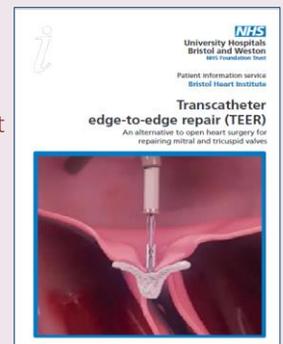
There is a short recovery time after the procedure with discharge home from hospital often achieved after 24 to 48 hours.

TEER has been expanding into more complex anatomy and it is now an emerging procedure in the congenital heart disease population. The team in the Bristol Heart Institute have performed successful TEER on a growing number of patients with congenital heart disease and differing underlying anatomy. 12 patients with congenital heart disease have undergone TEER in Bristol as of September 2024 with more awaiting the procedure. As experience continues to build, this technology is being more readily considered as an alternative to surgery in selected patients.

Dr Stephanie Connaire is leading a session on long term outcomes in paediatric and adult Fontans at the Level 1 (Bristol) and Level 2 (Cardiff) Cardiac Nurse Specialist Away Day in Cardiff, in January 2025.



To access the patient information leaflet, use the QR code or link below



https://uhbw.mystaffapp.org/14358/document_view.pdf



What's Occurring? Paediatric Cardiac Nurse Specialist Teams



By Jo Bailey, Paediatric Cardiac Nurse Specialist, Bristol Royal Hospital for Children

2024 proved to be a busy year for the Bristol Paediatric Cardiac Nurse Specialist team, due to depleted staffing numbers. We had two team members on maternity leave and one seconded to a different nurse specialist team.

However, we were delighted to welcome two new members to the team. **Emily Putman** brings with her a wealth of experience from her previous roles working in Intensive Care, and as a Nurse Specialist at Great Ormond Street, predominantly supporting infants on the Home Monitoring Programme. We are also delighted to welcome **Carrie Cherrington** who joins us on secondment for 9 months from the Cardiac Research team. Carrie has many years' experience working on Dolphin Ward and within Cardiac Research, and we are really pleased to have them join the team. We are also very pleased to welcome **Ella Houghton** back from maternity leave.

Funding has been obtained for a new permanent role for 0.5 WTE within the Cardiac CNS team. Congratulations to **Zoe Jordan** from the Paediatric Bristol CNS team who has successfully been appointed to this role and is now splitting her time 50/50 between patients with CHD and patients with Inherited Cardiac Conditions (ICC).

Zoe (pictured right) will be working closely with the ICC Paediatric Consultants, Dr Armstrong, Dr Shortland and Dr Spentzou as well as the ICC nurses in adult services in Bristol and throughout the UK.



Zoe is currently running screening clinics for families affected by Hypertrophic Cardiomyopathy, in conjunction with the Cardiac Physiology (CP) team, and the plan will be to extend these Nurse/CP led clinics to cover other inherited conditions such as Brugada. Zoe's remit will also cover referring families for consideration of genetic testing and helping co-ordinate testing and results.

The role and service provision will continue to evolve over the coming months. If you have any queries regarding the Paediatric ICC service, or queries regarding ICC patients, please do contact the team.

Cardiff site visit hosted by South Wales Paediatric and Adult CNS teams

By Michelle Jarvis, Network Manager

We had a great time visiting and catching up with the Cardiff CNS teams in October. It was brilliant to also be able to join the ACHD Multi-Disciplinary Team (MDT) to meet the full team and hear the specific discussions and some of the pathway work being picked up / planned around dental, contraception and potentially menopause! It was lovely to be able to meet with the ward staff too.

With Karina, Claire and Amy we were really interested and impressed to hear more about the transition model and service, as well as the very innovative piloting of an INR testing drive through!

Left to Right:

Karina Parsons-Simmonds
Claire Logan
Becky Lambert
Amy Godwin
Michelle Jarvis



By Karina Parsons-Simmonds, Paediatric Cardiac Nurse Specialist, Noah's Ark Children's Hospital for Wales

In South Wales, we are pleased that **Amy Scarlett's** CNS secondment is now permanent (full time), as is **Karina Parsons-Simmonds**, Team Leader role (part time).

In the last 6 months, the team have established an ACEi challenge nurse led clinic, which is running very smoothly and, as it is being held on the Investigations Unit, it is reducing day case footfall on Pelican (cardiology) Ward at the Noah's Ark Children's Hospital for Wales.

We are also launching a drive through INR clinic, utilising an existing portacabin that the Paediatric Diabetes team use. This will also reduce patient footfall on Pelican Ward, and hopefully reduce family anxieties around hospital parking.

Amy Scarlett, **Karina Howell** and **Jemma Gammond** have also developed a cardiac study session for newly qualified nurses and ward staff, on commonly seen conditions on the paediatric wards.



Left to Right:

Michelle Jarvis
Kindre Morgan
Samantha Swanson
Becky Lambert
Sarah Finch

The Cardiff and Bristol Paediatric and Adult Cardiac Nurse Specialist teams Away Day is being hosted in Cardiff in January 2025. This Network event usually occurs twice a year with representatives from the cardiac ward teams too.



Developing the Nurse Specialist Role in Level 3 Peripheral Centres

By Becky Lambert, CHD Network Lead Nurse



In November 2024, I was asked to present at the British Congenital Cardiac Association (BCCA) Annual Conference in Dublin, on the development of the Nurse Specialist role within Level 3 centres (peripheral hospitals). Following the presentation, several CHD Networks across the UK contacted me, seeking further information or requesting similar presentations for their teams.

We are fortunate within our South Wales and South West CHD Network to have an exceptional group of nurses dedicated to developing the role of local Nurse Specialists in our peripheral centres, both for paediatric and adult care. This role is pivotal in supporting the Network to deliver seamless, high-quality, and equitable care to patients, irrespective of their geographical location. These local Nurse Specialists collaborate closely with, and learn from the Specialist Nurses in Bristol, offering localized expertise and serving as a key point of contact for patients.

Impact of the Local Nurse Specialist Role

As part of our commitment to excellence, the Network team recently conducted self-assessments in 17 centres across the South West region. These assessments measured compliance with NHS England's standards for Congenital Heart Disease (CHD). A significant finding was the positive impact of having local CHD/ACHD Nurses in place, which resulted in:

- ✓ **Improved standards compliance:** centres with local CHD/ACHD Nurses consistently demonstrated better adherence to CHD standards.
- ✓ **Enhanced patient care:** patients benefitted from improved access to expertise and continuity of care.
- ✓ **Operational efficiency:** The role has contributed to freeing up consultant time, leading to reduced waiting lists and lower DNA (Did Not Attend) rates.

The implementation and development of the local Nurse Specialist role is a key strategy in ensuring equitable and high-quality care across our Network. The work of these nurses is instrumental in fostering collaboration, optimizing resources, and, ultimately, improving patient outcomes.

Here is some feedback from patients on the difference a local nurse makes to them:

"Reassurance is key and the key to reassurance is continuity, it's having that one person you trust, a professional who comes to know you and your family dynamic." Patient with CHD

"Our amazing local nurse specialist has become a friendly, and very trusted face and voice, she knows us well enough that she can make a well-informed assessment of any situation, and that can make a world of difference." Patient with CHD

PAFTAS 2024 Award Nominees

Paediatric Regional Awards for Training Achievements

Nursing Role Model of the Year Award Nominee, Nina Worrin



Nina, a Cardiac Nurse at the Royal Cornwall NHS Hospital, has been recognised for exemplifying the principles and values of nursing and inspiring her colleagues through her work. Dr Katy Huxstep, Consultant Paediatrician with Expertise in Cardiology at the Royal Cornwall Hospital, shared her reflections:

"Nina has worked as our cardiac nurse for nearly 2 years. She has become an integral part of our team, and we really couldn't do without her. She has really pushed herself this year to develop her role, support patients, develop clinical skills and new pathways."

"I know she has been such a support to so many patients and families... She supports our physiologist brilliantly and also makes my life as a consultant so much easier – she has time for that personal touch, especially for patients which is so important... I can't wait to support her development and confidence over the next few years."

Multidisciplinary Hero Award Nominee:

Gemma Wright, Cardiac Physiologist at Royal Cornwall Hospital

Non-Clinical Staff of the Year Nominees:

Heather Smith, Paediatric Cardiology Secretary at Royal Cornwall Hospital, and Helen Elliot, Service Manager for Cardiology at the Royal Devon University Hospital Northern site (Barnstaple), are also Network members.

Consultant Hero Nominations

Several members of the Network have also been nominated for the Consultant Hero Award for embodying the principles of the Royal College of Paediatrics and Child Health (RCPCH), being role models for trainees, inspiring their colleagues, and uniting the multidisciplinary team (MDT).

- Dr Emma Hulbert-Powell (Plymouth)
- Dr Katy Huxstep (Truro)
- Dr Justin Thuraingham (Exeter)
- Dr Nagendra Venkata. (Exeter/Torbay)

Watch this space! Award ceremony at the end of March: <https://paftas.net/12dop24/>





Education and training

One of the Network objectives is to support and promote training and education opportunities for our healthcare professionals involved in the care of patients with congenital heart conditions. Details of training and education events can be found on the Network website (www.swswchd.co.uk).

New Psychology 'tea and talk' webinar series 2024/25

An online CPD psychology day was held in June 2024, led by the Clinical Psychology Leads in the Network, for professionals working with paediatrics and adults in cardiology, critical care and CHD. The day covered different psychological models used in cardiology; giving the opportunity to hear from patients, clinicians, and family members about their lived experiences; and to reflect and connect with colleagues in break-out rooms.



Following feedback on topics that sparked particular interest, a new 'tea and talk' webinar series was launched in the autumn of 2024 providing a supportive space to focus on important but often overlooked conversations around having the courage to be creative in what we do and to step out of the norm. As well as focused sessions on psychological models and practical applications in cardiology. More sessions are planned in 2025!

Cardiology Education (PEC) Forums, 2024/25

This hybrid event hosted by Dr Nigel Osborne, was held in Exeter providing education pitched at Consultants with Expertise in Cardiology (PEC) level, with specialist speakers mainly from Bristol. Topics included Brugada; Marfan syndrome, genetics of arrhythmia, and pregnancy and contraception with CHD. Following the popularity of this hybrid event, we are excited that a further education forum is planned in July 2025.



Transition Study Event, December 2024

This education event focused on CHD and featured a new talk on setting up a transition clinic in a Level 3 peripheral centre presented by Grace Pye, Children's Cardiac Transition Nurse at the Royal Devon University Hospitals. As well as a new talk on early advanced care discussions with young people, presented by Sheena Vernon, Network Lead Nurse.



ACHD Study Day, October 2024

The 22nd Annual ACHD Study Day was held in October 2024. This is a day for nurses, midwives, physiologists and doctors caring for adults with congenital heart disease from across our Network. It is also attended by staff from the paediatric services who are keen to understand what happens when patients transfer to adult services, and this informs their discussions with the patients and their families.

The theme of the day was Fallot's Tetralogy. Talks delivered included surgical and cardiology treatment options, management of pregnancy in Tetralogy of Fallot, imaging options, psychological challenges patients may face, and a story from a patient about his journey with the condition. 85 delegates attended with positive evaluation!



What's coming up regionally?

- ❑ CHD Network Psychology 'Tea and Talk' webinars 15th January 2025 & 17th March 2025 - Online
- ❑ Paediatric CHD Study Day: Care of the patient with an Atrio-ventricular Septal Defect (AVSD) 25th February 2025 - Bristol
- ❑ Cardiology (PEC) Education Forum 18th July 2025 - Hybrid
- ❑ ECHO ACHD webinars, dates throughout the year – online



SWSW CHD Network NHS Future Platform

This platform for healthcare professionals stores training and education resources, and is currently home to the:

- + Transition study event webinars
- + Fetal cardiology webinar series
- + Paediatric cardiology nursing webinar series
- + Paediatrician with Expertise in Cardiology (PEC) platform
- + Psychology webinars
- + ACHD study day webinars & resources
- + Research forum webinars

If you think a professionals education page would be useful for your team/staff group, please do let us know.

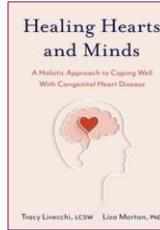
Do also check out the 'Events' calendar on the Network website for upcoming events
www.swswchd.co.uk



A Holistic Approach to Coping Well with CHD

By Pauline Aiston, Clinical Psychologist, Bristol Heart Institute

In 2024, we launched the first peer led adult congenital heart disease (ACHD) online support programme in England, based on the 'Healing Hearts and Minds' book by Livecchi and Morton (2023). This book shares the authors lived experience of CHD and offers evidenced based strategies for facilitating living well alongside this condition. It recognises the biological, psychological and social impact of living with CHD.



The idea of the group evolved from numerous observations in the ACHD psychology clinic, where many young adults and adults would express a sense of isolation and disconnect, when sharing their lived experience of having CHD.

A group facilitated by the ACHD Psychologist at the Bristol Heart Institute and led by those who live with CHD, evolved that aimed to reduce felt social isolation and increase a sense of connection. The eight online group sessions explored a holistic approach to living with CHD covering:

- ☺ Living well with a congenital heart condition;
- ☺ Understanding the body's response to anxiety and trauma;
- ☺ Building resilience.

Feedback from the group was really encouraging showing attendees grew in 'compassion' and 'connection'.

"For once I feel like other people understand"

"I would not have been able to make the feeling of connection, other than within this group."

EuroACHD 2024

The 15th European Meeting on Adult Congenital Heart Disease



A poster of the evaluation of this new support group was accepted for presentation at EuroACHD 2024, held at the Royal College of Physicians, London.

New groups planned for 2025

Due to the success of the first two online groups, more groups will be running in 2025. The group is for young adults and adults with CHD, who are registered with a Bristol (Visiting) Consultant Cardiologist. Please get in touch if you would like to attend by emailing PHS@uhbw.nhs.uk

The theme of facilitating connection and reducing isolation in the ACHD patient group continues. Funding was secured for a refurbished space within BHI out-patients area - so young adults with CHD that are waiting for their medical appointment, can choose to connect. You can read more about this on page 8.

ACHD ECHO Webinar Series

This Network ACHD Echo webinar series led by Senior Echocardiographers Gui Rego and Sarah Fairbairn, has been hugely successful with thanks to all involved.

This is a series of online talks to provide education and support for anyone working in ACHD ECHO across South Wales and the South West of England, especially those who want to pursue the British Society of Echocardiography (BSE) CHD accreditation. The 1-hour webinars have a CPD credit approved by the BSE.

The monthly sessions commenced in January 2024 and have covered a range of pathologies with different speakers. The sessions have been very well received with excellent attendance (average of 97 registrants).

This is a brilliant resource with the recorded webinars available on the CHD Network Future Platform for healthcare professionals.



ECHO Exam Preparation

By Owen Burgess, Deputy Head Cardiac Physiologist

In October 2024, five members of the team at University Hospitals Bristol and Weston sat the European Association of Cardiovascular Imaging (EACVI) Congenital Echocardiography Accreditation exam: Dr Elizabeth Silverwood and Marie Frost from Bristol Royal Hospital for Children, along with Joao Pereira, Joana Timoteo and Jance Manalo from the Bristol Heart Institute.

All have studied hard and were supported with pre-exam study sessions by Dr Srinivas Narayan, Dr Alison Hayes and Owen Burgess. We wish them all well and fingers crossed for positive results!

If any staff in the Network are planning to sit either the EACVI or British Society of Echocardiography (BSE) congenital exams in 2025, please get in touch! We'd love to help.



New Youth Space at the Bristol Heart Institute



The Bristol Heart Institute outpatients waiting area has been enhanced with calming wall murals with thanks to donations to Bristol and Weston Hospitals' Charity. The new and improved space will help young patients as they transfer from children's services to the adult setting at the BHI. It also supports patients who present with learning disability or who are neurodiverse.

We caught up with Xander Patel Cook, Senior Congenital Heart Disease Youth Worker (pictured above), who is externally funded and employed by Somerville Heart Foundation and holds an honorary contract:

"I started this project nearly two years ago... In paediatrics, the environment is well-suited to children and some young people, but when they move to the adult hospital it is a very sudden and drastic change to a "hospital" looking environment: white walls and limited things to look at on the walls while waiting for a clinic appointment.

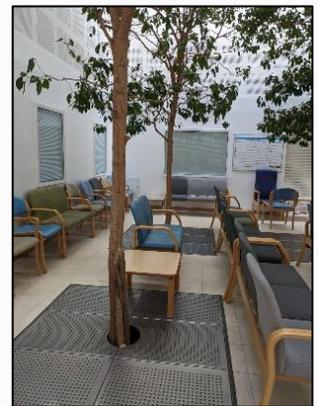
Initial feedback obtained from some patients with neurodiversity, about the original out-patient area was that walking through a busy waiting room increased their anxiety and they sought a space where they felt more protected, safe, and relaxed.

We felt the area identified, would provide a clear walkthrough that avoided too many crowds and that the back wall may also help patients to feel more protected.

Regarding all the young people that we see in clinic, a common theme seemed to emerge – the majority felt alone in regards to their heart condition and their desire to connect with other young adults who are facing similar challenges to themselves. It is hoped that by providing a shared space for young adults to convene this may facilitate connection, communication, and a shared exploration of what it feels like to navigate life alongside a heart condition.

The Learning Disabilities team and the young people I work with, engaged in the consultation process, and we now feel that we have achieved a space that is fit for purpose.

The young people consulted felt that having seasonal variations in the windows was in-keeping with the space and may offer a sense of calm.



Before ➡

After



Feedback from Emily (young person with CHD)

"The space makes a huge impact as a young person coming into hospital... Having spaces dedicated to young people takes some of the stress away allowing an area to meet other young patients."

The artwork provides some mental stimulation and mindfulness in a usually dull and often frightening environment. They allow that trip to hospital to be a bit more enjoyable, which makes a world of difference for someone's mental health, as well as ensuring patients are consistent and co-operative in coming to all their appointments where anxiety may prevent them."



A warm welcome

Introducing Becky Lambert, Network Lead Nurse

In June 2024, we were delighted to welcome Becky Lambert in the role of Network Lead Nurse, working part-time with Sheena Vernon. We caught up with Becky to find out more:

I am delighted to have been given this opportunity and to be part of a fantastic team, committed to improving care for CHD patients across our region.



What is one of your proudest achievements?

I have been a nurse for over 38 years. I trained in Exeter, then worked in Oxford, before moving back to the South West of England nearly 30 years ago. One of my proudest achievements in my nursing career, is setting up the Nurse Specialist role in Taunton. I believe that this has given our local patients a better service, and I am keen to support other local centres in our Network to do the same.

What else are you passionate about?

I am also passionate about improving our transition services Network-wide, as I have seen what a positive impact effective transition can have on patients' journeys.

What do you enjoy doing outside of work?

Out of work, I am married to Paul, a Consultant Endocrinologist in Taunton and a mum to 4 adult children (also now a proud grandmother to Tommy – pictured above). I am part of the leadership team of a local community church and when I get any spare time, I enjoy reading, walking, and catching up with friends over good food and wine. I completed the Moonwalk earlier this year (26.2 miles overnight across London) and as a result, find myself keener on walking shorter distances in the future!



Becky with Michelle Jarvis and Sheena Vernon



Becky with local nurses – Grace (Exeter), Nina (Truro), Jenni Stirling (Hywel Dda) and Becky (Taunton)



Update on team changes

We bid farewell to Professor Graham Stuart, Consultant Cardiologist at the Bristol Royal Hospital for Children, who retired after 42 years of NHS service (see page 10).

We also bid farewell to Dr Manish Gandhi, Consultant who retired from Exeter, and Dr Jennifer Holman, Consultant Paediatrician with Expertise in Cardiology who retired from Gloucester, and congratulate Dr Pradeesh Mappa to this role on his transfer from Swindon to Gloucester. We also said goodbye to Dr Simon MacDonald in Cardiff.

We are pleased to welcome Dr Frances Hanlon, PEC in Swindon, Samantha Swanson, ACHD Clinical Nurse Specialist, and Amy Godwin, Paediatric CNS, both in Cardiff. We also welcome Emily Putman and Carrie Cherrington, Assistant Paediatric CNS in Bristol, and welcome back Bethany Brock.

Congratulations to Dr Nadia Hajiani as the new Lead for South Wales Paediatric Cardiology. We want to extend our congratulations to Dr Alan Pateman who has been appointed Clinical Director at University Hospital Wales and thank him for all his work as Cardiology Lead over the last few years.

At the Bristol Royal Hospital for Children, we welcomed Dr Naychi Lwin, Consultant in Paediatric Cardiology with subspeciality interest in Intervention. We congratulated Dr Tim Murphy on his appointment as Clinical Director of cardiac services at BRHC, as well as Dr Patricia Caldas who took on the BRHC Lead Cardiology role. We thank Mr Andrew Parry for his many years as Congenital Cardiac Surgical Lead and congratulate Mr Shafi Mussa on his appointment as Mr Parry's successor. We thank Dr Andy Tometzki for his work as outgoing Cardiology Lead

Thank you for your support and commitment to your local CHD services and to the Network.



Retirement of Cardiology Legend: Professor Graham Stuart

After 42 years of hard work and dedication to the NHS, Professor Graham Stuart retired from service in July 2024. Graham has touched all corners of our Network and will be missed by all of his colleagues and even more so by his patients and their families.

Training and appointments

Following his training in Dundee, Glasgow, Newcastle and Birmingham, Graham was appointed a Consultant Cardiologist in Cardiff in 1993. In 1998, he moved to Bristol and began setting up the Adult CHD service (previously known as 'GUCH'), building the team, not only in Bristol but in peripheral clinics in Truro, Taunton, Swindon, and Cheltenham. He also continued to work in paediatric cardiology in the Bristol Royal Hospital for Children, specialising in electrophysiology, pacing and inherited cardiac conditions.

Service development

Along with Dr Rob Martin, Graham expanded the ACHD service in Bristol, which is now one of the largest in the UK. From one nurse, two secretaries and two cardiologists mainly doing paediatric cardiology, there are now five full-time ACHD cardiologists, four middle grade doctors, five secretaries, four specialist nurses, a psychologist and a coordinator!

Academia and research

Graham has a flourishing academic and research portfolio. He completed an MSc in Sports and Exercise Medicine (University of Exeter) and Certificate in Genomic Medicine in his spare time (!) and was made an Honorary Associate Professor in Sports and Exercise Cardiology at the University of Bristol, having published over 100 scientific papers and 16 book chapters. Graham was an excellent teacher and always wanted to help colleagues progress. He also did an enormous amount of work for cardiac charities and was a Trustee of the Somerville Foundation for many years.



Pioneer: Joint Cardiac Obstetric Clinic

In 2001, Graham set up the joint cardiac obstetric clinic at St Michael's Hospital in Bristol with Dr Sue Sellars, Obstetrician, providing one-stop setting in which to see pregnant women with heart disease, the majority of were ACHD patients. This has grown from a handful of patients being seen once a month to around 50 per month in two separate clinics.

National roles

As an expert on congenital electrophysiology, and for his leadership skills, Graham was often involved in national roles, such as being the Chair of the Clinical Reference Group for the NHS England ACHD Standards, member of the NHS England ICC Service Specification review group and the BHF/NHS England Sudden Death Project Steering group. In 2008, he was given an award by the Arrhythmia Alliance for his "Outstanding contribution to Electrophysiology Services".



Sports Cardiology

One of Graham's greatest passions is sport, and he was often to be found running marathons, completing Ironman triathlons and most notably rowing across the Atlantic!

He has an interest in Sports Cardiology and ran a successful private practice in this field, as well as setting up NHS clinics for athletes to get specialist advice. Whether it was professional sports people or chronically ill limited patients, Graham has always been a tireless advocate for increasing physical activity in his patients to improve their health.

Some quotes from colleagues...

"Graham has always been the most supportive, honourable and genuinely kind colleague and friend. A lifelong student of medicine, striving for the best in every patient, a welcome beacon of brilliance. Truly lives his Christian values".

"Graham was a great leader - he knew how to build teams and grow / evolve services and his patients loved him!"

"A genuine man, an outstanding doctor, a great teacher and a selfless friend. His strict morals amazingly blended with his caring kindness".

The retired life

It is unlikely that Graham will now be putting his feet up. He is busy with church activities, spending time with his children and grandchildren and of course... doing degree in theology! He will also be continuing to support the Scottish rugby team with a wee dram of whisky in his hand, a job in itself!



New Network Clinical Guidelines

Clinical guideline for pregnancy and contraception in patients with CHD for Paediatric Cardiologists and Paediatricians with Expertise in Cardiology

This new guideline was created by Dr Stephanie Curtis, ACHD Consultant Cardiologist, and Dr Idoia Grange, Consultant Cardiologist at University Hospitals Bristol and Weston. This was in response to requests across the region, mainly from Consultant Paediatricians with Expertise in Cardiology, via the South West England Level 3 self-assessment reviews held during the Summer of 2024, and a very well-received talk on this topic by Dr Curtis at the South West Cardiology Education Forum (Exeter, September 2024).

The new guideline was finalised and signed off at the Network Governance meeting in November 2024 and is available on our Network website and on the MyStaff document management system for healthcare professionals:

https://uhbw.mystaffapp.org/15573/document_view.pdf



Adult CHD Joint Cardiac Conference Terms of Reference (Bristol Heart Institute)

A findings and recommendations report has been produced in relation to improvement opportunities for the Adult Joint Cardiac Conference (JCC) meeting following a scoping survey to JCC members across the region. The Network team and the Bristol Heart Institute ACHD leads met to discuss the findings and many recommendations have now been implemented.

A revised terms of reference for the ACHD JCC has been published. Significant improvement to performance has already been identified since changes were made in both the numbers of cases being reviewed and the reduction of the Adult JCC waiting list (reduced by 87% in 4 months!). There has been excellent engagement and much positive feedback.

https://uhbw.mystaffapp.org/15572/document_view.pdf

The paediatric cardiology JCC review is currently in progress with the support of teams across the Network.

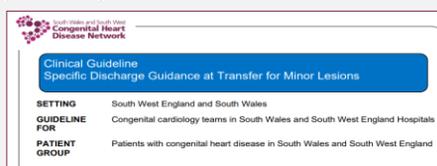


The Joint Cardiac Conference (JCC), also sometimes known as an MDT (multi-disciplinary meeting) usually meets weekly and is attended by specialist health professionals in congenital heart care across the Network. The group discusses patient cases, often to consider potential intervention or surgical options.

Specific discharge guidance at transfer for minor lesions

This guideline entitled, 'Specific Discharge Guidance at Transfer for Minor Lesions', was developed to enable Paediatric Cardiologists and Paediatricians to know which patients can be safely discharged from ongoing cardiological care.

The is available on our Network website
https://uhbw.mystaffapp.org/14286/document_view.pdf



Additional Needs & Learning Disabilities Directory of Contacts

A directory of Learning Disabilities team contacts across South Wales and the Southwest has been published, with thanks to Molly Waters, Learning Disability and Autism Liaison Nurse, and Sheena Vernon.

The purpose of the directory is to provide easy signposting to local teams who may be helpful in supporting patients with congenital heart disease as they attend their outpatient appointments, investigations, cardiology interventions or cardiac surgery.

The directory is saved on the CHD Network website together with many other resources:

<https://www.swschd.co.uk/en/page/clinical-information-learning-difficulties>



Did you know...

There is an 'easy read' version of the Ready, Steady, Go transition programme

<https://www.swschd.co.uk/en/page/teenagers-young-people-and-their-carers>



Network update

By Michelle Jarvis, CHD Network Manager



Happy New Year to all across the Network!

Network colleagues across the South West England Level 3 centres were busy in 2024 completing their self assessments against the NHS England 2016 Congenital Heart Disease Standards. The centres scored their compliance against each standard and then met for a review session with wider Trust colleagues and the Network team.

It was brilliant to meet with all 17 Level 3 CHD teams (paediatric and adults), albeit virtually, to hear about their services and further explore areas of success, innovation and areas of challenge. The self-assessment review sessions were positive and informative, with teams across all 17 services showing passion and enthusiasm to improve and make their services equitable for CHD patients and their families.

It is encouraging to see that the majority of CHD standards are met across the region, with some centres excelling, and that there is a continued focus on service development to ensure the best quality of care for patients. Recommendations have been made with the intention of helping each centre to identify where further investment and focus on improvement is needed.

Following the success of the South West England Level 3 self assessments, the Network team very much look forward to the reviews planned for this coming year with the Level 1 Specialist Surgical CHD Centres (Bristol Heart Institute and Bristol Royal Hospital for Children) and the Level 2 Specialist CHD Centres (University Hospital of Wales, Cardiff).

As we head into the new calendar year, we start to think about the Network work programme for the next financial year (2025/26) and refreshing our workplan to ensure we remain focused on the aims and objectives of the Network in achieving high quality, safe, effective and sustainable congenital heart disease services in South Wales and the South West England. Network projects to support the sharing of best practice and to address the key challenges identified through the self assessment process will be prioritised within the CHD Network workplan moving forward.

Please do get in touch with you have any thoughts or suggestions for the workplan or if you would like to discuss further (michelle.jarvis@uhbw.nhs.uk).

I look forward to another exciting year working together in 2025.



Images: Network colleagues at the Royal Devon University Hospitals paediatric CHD review session (left) and adult CHD review session (right)

Network dates for your diary!

Key Network meetings:

Thursday 13th February 2025:
Network Board and M&M

Tuesday 22nd May 2025:
Network Board & Clinical Governance

To keep up-to-date with Network news and our publications please follow us on X @CHDNetworkSWSW



Staff Photographic Competition #6: 'Wildlife across the Network'

Throughout September/October 2024 we received photos from CHD Network staff, who have taken photos whilst out and about, on a trip away or during their commute to work. To see all the entries and also to peruse the galleries of previous entries, please visit the Network website:

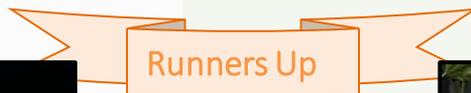
<https://www.swswhd.co.uk/en/page/photographic-competition>

The theme of nature and wellbeing has never been so relevant; getting out into nature can have a huge positive impact on our mental health as well as physical health.

We are pleased to announce that **Emma Mugford**, Medical Secretary in Swansea, South Wales, is the winner capturing this incredible image: 'celebrating the pollinators: a little bee feeding from a purple *Succisella inflexa*' captured in her own garden.



5



'Hedgehog on the driveway'

Nina Worrin, Cardiac Nurse, Royal Cornwall Hospital



'A huge stick insect in the garden'

Dr Katy Huxstep, Consultant Paediatrician with Expertise in Cardiology, Royal Cornwall Hospital

The staff competition will open again ahead of the summer newsletter – we look forward to seeing your creative images!
For further information please contact the CHD Network team via Rachel.Burrows2@uhbw.nhs.uk.



Patients at the heart of our Network: Lillian's story

By Suzanne, Lillian's mum

with the support of The Grand Appeal, the dedicated charity for Bristol Children's Hospital

When Suzanne and Wayne, from Powys in Wales, learned at their 25-week scan that their baby girl would be born with a life-threatening heart condition, they were devastated. Treated immediately after her birth in St Michael's Neonatal Intensive Care Unit (NICU) and then for weeks in Bristol Royal Hospital for Children, Lillian has been through a lot in the first few months of her life. But their miracle baby continues to be just that – and now, things are looking very hopeful for this loving family. Suzanne, Lillian's mum, tells us her story.

"Five years ago, we were told we'd never have children – that my endometriosis would make it impossible. In 2023, just after a routine operation for it, we heard the most amazing news: I was pregnant. Then, at just 12 weeks, our two foster children, Anastasia and George, joined us. Very quickly, we went from having no children to having three. Lillian, our daughter, is our little miracle baby. She's a fighter and she's everything. *Just everything.*

We found out about Lillian's heart issues at our 25-week scan. We were devastated but no matter what the odds were, we knew we had a little warrior, and we'd love her regardless. She was born in St Michael's Hospital and was transferred to NICU straight away to stabilise her. We were there for four days in total – I was an inpatient, too, while I recovered from a very difficult birth – and *Cots for Tots*, the dedicated charity for St Michael's Neonatal Intensive Care Unit (NICU), put us up in *Cots for Tots House*, just across the road, where Wayne stayed. On day four I was discharged, and Lillian was moved to Bristol Royal Hospital for Children's Dolphin Ward, the cardiac High Dependency Unit, which looks after children with heart issues. The Grand Appeal moved us from *Cots for Tots House* to Paul's House, so we were still just minutes away from Lillian.

We were told when Lillian was born that she had Transposition of the Great Arteries, which meant the main arteries in her heart were the wrong way round and she couldn't pump oxygenated blood. Effectively, she was running on two separate circuits, and the heart wasn't able to do its function. The arteries needed to be switched around, so she had open heart surgery at just 11 days old. Without the surgery, we would've only had a month with her. But it was successful and she's doing so well now. She should lead a full and normal life.

Everywhere we went we found lovely staff members who doted on Lillian. Everyone was enraptured by her and it was beautiful to see. I had a difficult, painful birth which involved forceps when Lillian's heart started struggling, but we had some great people who helped us have a safe delivery.

Initially, her heart surgery was moved because an emergency case came into the hospital suddenly. Lillian was fine until her lungs began overcompensating for the lack of oxygen her heart wasn't able to pump. When her condition worsened, a wonderful surgeon cleared his schedule then and there to perform the surgery she needed and prevent the unthinkable. We are extremely grateful for this, and we will never forget the surgeons who stepped in and helped to save her life.

There were some post-operation complications which meant they had to reopen her chest at 2am. It was terrifying, but the surgeon went the extra mile to check in and make sure she pulled through. He kept us informed and reassured us during the worst time of our lives. It helped more than words can express.

That day was my first official Mother's Day. I felt like a horrible mum because I couldn't do anything to help my baby. But then, someone in the Paediatric Intensive Care Unit (PICU) wrote me a card 'from' Lillian, and gave me some beautiful flowers, and it was one of the most touching moments I've ever experienced. It still makes me cry whenever I think about it.





...Lillian's story continued

There are some wonderful memories that stick in my head when I think about our time in Bristol Royal Hospital for Children. On the PICU, a lovely harpist from Arts Unleashed, The Grand Appeal's arts programme, came to perform some Disney songs for the children on the unit. It was a beautiful moment. It was also so nice to see all her wires removed for the first time after surgery so we could put her in her first outfit.

Everyone was so lovely and really acted like Lillian was a special little girl. People from different wards came to see her as they'd heard about 'the beautiful little baby on Dolphin Ward' and wanted to see for themselves. This made us, as parents, feel a lot more relaxed about the situation she was in because she had so many people giving her good wishes.

We live in Powys, in Wales. It's a two-hour drive to Bristol on a good day. One of our biggest concerns, after learning we'd need to be in Bristol for four to six weeks while Lillian got better, was how we would afford it. It gave us a lot of stress we didn't need – Lillian needed the surgery, but how would we stay by her side?

We'd stayed in Cots for Tots House while we were in NICU, but when we found out about the free accommodation available to us in Paul's House, just across the road from Lillian, I cried. We'd have a home for as long as we needed, with huge convenience and little cost. We saved so much money not just on where we were staying, but food too, because there was a full kitchen we could use to cook instead of having to get takeaways.

We still had two foster children at home, Anastasia and George. My dad had them throughout the week, so their schoolwork wasn't interrupted, but it was so difficult. They were just starting to settle in and form a routine, and suddenly, Wayne and I had to spend months in and out of Bristol.

Anne, The Grand Appeal's Family Accommodation Manager, was amazing. Nothing was too much trouble for her. She gave us two extra fold-down beds so the kids could stay at the weekend. This was vital to us – it meant our foster children knew they were still an important part of our family, and we wouldn't go weeks without seeing them. Anne really is an asset to Paul's House, as are the wonderful housekeepers there.

In fact, one of the lovely housekeepers was my rock for a while – when Lillian was in surgery, and I felt like I was falling apart, she always stopped to talk to me and make me feel better. I was so grateful to her.



Wayne and I spoke to a few families who were staying there, and we shared stories. It reassured us that we weren't the only ones going through a difficult time and made us realise it could've been much worse.

Other people's success stories helped. Hearing others talk positively helped us see the light at the end of the tunnel. We felt so fortunate, and it put into perspective that although Lillian needs this surgery, she will be fine and lead a happy, healthy life. Our little girl was fighting, and we couldn't lose hope for her sake.

Paul's House is so needed. Without it, I don't think we would've been able to cope in such a trying time. It felt reassuring to be with other families who were going through similar journeys, so we could all go through the ups and downs together. It gave us a sense of community. The house was everything we needed both financially and emotionally, because it helped us focus on what was important: Lillian.

We're three months on, and Lillian is doing so well. Her heart surgery scar has healed nicely. She's very active and alert and you can tell she's itching to get moving. She's holding her head up very well and trying to sit up already and is always babbling away. She's going to be a chatterbox like her mummy.

We are so proud of her – and we're excited to see what the future holds for our perfect family."



The Grand Appeal is a dedicated charity for the Bristol Children's Hospital. It supports hospital staff as well as patients and their families from across South Wales and the South West of England. Its latest project is The Grand Appeal's Patient Hotel, which is a groundbreaking new outpatient facility, which will allow sick children to finish their treatment in a home-from-home instead of a hospital bed.

Find out more about The Grand Appeal at: www.grandappeal.org.uk



Useful contacts

We provide life-long support and advice to patients and their families throughout their whole journey with us.



Adult CHD Clinical Nurse Specialist Team
(Bristol)

Available: Mon to Fri, 8am to 4pm

Email: bhiachdnurses@uhbw.nhs.uk

CNS Telephone: 0117 342 6599

BHI Outpatient Department: 0117 342 6638

Cardiac Admissions Office: 0117 342 9444

Pacemaker/ICD advice line: 0117 342 6515

Adult CHD Clinical Nurse Specialist Team
(South Wales)

Available: Mon to Fri, 9am to 4pm

Email: achdnurse.cav@wales.nhs.uk

CNS Telephone: 029 2184 4580

Appointments & non-clinical queries: 029 2184 3892 or via achd.cav@wales.nhs.uk

<https://cavuhb.nhs.wales/our-services/adult-congenital-heart-disease-achd-service/about-the-adult-congenital-heart-disease-achd-service/>



Paediatric CHD Clinical Nurse Specialist
Team (Bristol)

Available: Mon to Fri, 8am to 4pm

Email: cardiacnurses@uhbw.nhs.uk

CNS telephone: 0117 342 8286

Appointment co-ordinator: 0117 3429281

Surgical co-ordinator: 0117 3428977

For any clinical queries and emergencies (out of hours), please contact Dolphin Ward via switchboard (0117 342 0000).

Paediatric CHD Clinical Nurse Specialist Team (South Wales)

Available: Mon to Fri, 8am to 4pm

Email: PaediatricCardiac.Cns@wales.nhs.uk

CNS telephone:

Cardiff & Vale 029 2184 5184

Bridgend, Merthyr, Rhondda 029 2184 7021

Gwent 029 2184 5524

Swansea and West 029 2184 4753

Transition care all areas age 13 to 18 years 029 2184 8046

Fetal care 029 2184 1746

Appointments and non-clinical queries: 029 2184 4749

Want to know more?

The Network website is for patients, families and clinicians.

We have information on:

- Patient leaflets
- Getting support
- Hospitals and clinicians across the Network
- Patient stories
- Patient pathways
- Clinical information
- Network meetings and training events
- Research

Please share your feedback on our newsletter by scanning this QR code with your phone or via the link

<https://forms.office.com/r/dSLx5mAK15>



Thank you for reading!

If you have any stories or ideas, you would like to share for the next edition in

Summer 2025, please contact

CHDNetworkSWSW@uhbw.nhs.uk

We welcome:

- Patient/family/staff/team stories
- Clinical news/updates
- Events
- Network related issues
- Anything else you think might be relevant!

The newsletter will be published twice a year.

Sign up for free

Join our mailing list today to receive the SWSW CHD Network newsletter directly to your inbox.

Send your email address to CHDNetworkSWSW@uhbw.nhs.uk requesting our newsletter