South Wales and South West
Congenital Heart
Disease Network

New Year 2026
Issue 18

Newsletter

Updates from
your CHD Network

Inside this edition

Clinical Director's introduction...2
Pioneering ACHD gang...3
Strategy event...4
Youth services...6
New 'getting support' resources...6
Paediatric Intensive Care...8
Medicines for Children...9
Education and training...10
Cardiac physiology updates...11
Welcome and staff changes...12
Network updates...13
Spotlight on Gloucester...14
Patient story...15
Useful contacts...16

Introduction from our Clinical Director
Dr Stephanie Curtis

Happy New Year to all of our Network colleagues, friends, patients and families!

We start 2026 with a newly refreshed Network strategy for the next five years. Having almost completed the Self-Assessment exercises across the entire Network, we look forward to preparing for the next year's work plan, fuelled by ideas born on our very successful Level 1 and Level 2 Strategy Day in September. This will include continued work on the paediatric Joint Cardiac Conference (JCC) multi-disciplinary team meeting, a new cross-Network imaging protocols task and finish group, and further focus on transition and transfer of care with new protocols and a standard operating policy (SOP) to try to ensure equitable care for all of our patients.

On the subject of young people, this newsletter focuses on many areas that are crucially important for patients. The amount of work that goes on behind the scenes by Xander Patel-Cook is formidable and he has made a big difference to the lives of many young people with complex congenital heart disease. The importance of psychological support and how much it is valued by the patients is reflected in this Newsletter, particularly in Debbie's story.

We are delighted to welcome two new substantive consultant colleagues to the Network. Dr Silvia Caroli is fully trained in adult and paediatric congenital heart disease and will be an invaluable link between the Level 1 (Bristol) services to improve communication and patient care. Dr Steph Connaire, a new appointment in Cardiff, further strengthens the Welsh ACHD team and continues to work in the Level 1 (Bristol) centre, further fostering the longstanding close relationship between the two departments.

The ACHD service at Gloucester Royal Hospital has gone from strength to strength, showing the importance of establishing the Clinical Nurse Specialist role. David Withers has made a big difference to patients in a short space of time, and I am proud to say that the Network has strongly and continuously advocated for the funding of this role, which at one point looked quite precarious. The local CHD Clinical Nurse Specialist is the linchpin for Level 3 (district general hospital) services, and we continue to support Trusts wherever we can in developing and funding these posts.

In previous newsletters, we have seen the cutting-edge interventional procedures that are being performed in our Level 1 centre. We are lucky to have such a pioneering ACHD interventional team that continually pushes the boundary of what is possible for our patients.

Read and enjoy!

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

Front cover photo credit: Rachel Wyatt, Portishead Marina (November 2025)

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

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Pioneering ACHD gang strikes again

By Tracey Johnson, Cardiac Radiographer, Bristol Heart Institute

Early May 2025 had us celebrating the first implant of a Harmony transcatheter pulmonary valve at the Bristol Heart Institute. It is specially designed to treat severe pulmonary regurgitation in patients with a native or surgically-repaired Right Ventricular Outflow Tract (RVOT). Congratulations to our amazing interventional team who always strive for excellence and embracing new technologies.

The awesome ACHD team, excelled again in autumn 2025, when they successfully completed an implantation list using the Edwards SAPIEN 3 Transcatheter Pulmonary Valve System with Alterra Adaptive Pre-stent. It is indicated for use in the management of paediatric and adult patients with severe pulmonary regurgitation with native or surgically repaired right ventricular outflow tract. The skill and expertise demonstrated were not lost on the industry representatives nor the proctor who travelled from Ireland to assist.

Celebrating excellence

British Congenital Cardiac Association Annual Conference

Many members of the Network attended the British Congenital Cardiac Association Annual Conference in November 2025. This was held at the Royal School of Physicians in London. It was a great opportunity to learn, share, and interact with colleagues from across the country and beyond.

The event attracted over 600 delegates with an interest in adult and paediatric congenital cardiology from across the UK, and beyond.

Attendees were representatives of a number of cardiac associations including:

- The Paediatricians with Expertise in Cardiology Special Interest Group (PECSIG)
- Congenital Cardiac Nurses Association (CCNA) - British Adult Congenital Cardiac Nurses Association (BACCNA
- British Congenital Cardiac Physiologists (BCCP)
- As well as CHD Anaesthetists and non-affiliated healthcare professionals.

Representing our Network, Becky Lambert (Lead Nurse) presented on personalised adjustments for complex patients with CHD; Susie Gage (Network Pharmacist) on attention deficit and hyperactivity disorder medications in children with cardiac conditions as a network approach; and Owen Burgess (Deputy Head Cardiac Physiologist) on the national congenital echo training programme.

Pictured above: David Withers (Specialist Nurse, Gloucester), Becky Lambert (Lead Nurse) and Hannah Williams (ACHD CNS Bristol)

Level 1 & Level 2 CHD Network Strategy Event

We held a collaborative and innovative face-to-face Network strategy working event in Bristol in September 2025.

This was a resounding success and provided an opportunity for the Level 1 (Bristol) and Level 2 (Cardiff) Paediatric and Adult CHD services to come together to consider the future strategy of CHD between the specialist services. This included discussing key issues, the problem solving of shared challenges, and to share strategies for the development of CHD services in the context of the national picture.

Who attended?

37 stakeholders attended the event with good representation overall across the centres and workforce groups, with active participation. Thank you to all involved!

What was on the programme?

During the morning session, we were delighted to be joined by Dr Emma Redfern, Medical Director for NHS England South West, who shared an overview of CHD in the NHS England landscape and the important role and value of Networks in the future. This was followed by a proposed refresh of the Network strategy, setting the direction for collaborative improvement. All four services then presented their 5-to-10-year vision, followed by Q&A discussions.

Following a networking lunch, workshop sessions were held to generate strategies for improving joint pathways, communications and tackling inequalities. This included:

- How can we improve information sharing in our Network in an era of rapidly evolving technology?
- How do we streamline pathways, for example, Joint Cardiac Conference (JCC) communication, local pre-operative and post-operative assessment?
- How do we prevent obesity in our patients and reduce health inequalities?

How did attendees find the day?

Feedback was very positive with comments including:

> *"It was really interesting and great to have time to think about strategy and 5–10-year plans. Really informative and good things were learnt from the Welsh team to implement in Bristol."*

> *"Networking opportunities… immensely valuable and worked well... as the group was about the right size. In our current environment we are constantly busy and often meet people for 1 or 2 minutes in the corridor. Being face to face and away from work was the perfect opportunity to be able to network."*

> *"Most useful…cross pollination between centres, between adult and paediatric services and allied health professionals. All talks were excellent and small group discussions very useful."*

… continued… Level 1 & Level 2 Network Strategy Event

What's next?

An action plan has been developed to address key areas of note with several initiatives already underway. The Network team have identified priorities for 2026/27 for inclusion in the workplan.

Beyond compliance: strategic vision 2025-2035

Following this, Dr Stephanie Curtis, Network Clinical Director, presented the draft refreshed Network strategy at the Network Board in November 2025. As a well-established reputable Network with clear governance structures, several of the centres within the Network fulfil/exceed the national CHD standards and there is excellent engagement from almost all centres to continually improve and collaborate, with a strong patient/family voice.

The focus is now on levelling up equity of care; delivering high quality services, informed by the latest clinical developments; and driving innovation through research, digital improvements and streamlined patient pathways for the future. We are committed to expanding the patient/family voice in shaping care; and sharing our model nationally.

The refreshed Network vision for 2025-2035:

- High quality standardised care is delivered in all centres, led by latest clinical developments, including seamless care between paediatric and adult services.
- Equity of access to services and equitable outcomes, regardless of geography.
- A strong and sustainable CHD workforce.
- Strong patient/parent partnership with representation from a variety of socio-economic and ethnic groups.
- A culture of fostering research, innovation, and digital integration.

Dr Curtis outlined for each of the above vision statements where the Network is now, and where we want to be, and how this could be achieved over the next 10 years.

ACHD Youth Worker: 2025 in reflection

By Xander Patel-Cook, CHD Youth Worker

Hi Folks, Xander here, the ACHD Youth Worker. For this edition of the Network newsletter, I thought I would have a look back at the past year and highlight some of the work that has happened in the youth service.

First off, let's talk about the Youth at Heart merger with the Somerville Heart Foundation (SHF). This completed in November 2024, when I and the Youth at Heart brand joined the Somerville Heart Foundation. You can read more about this on the Somerville Heart Foundation website. Speaking of the SHF website, the youth services page has been updated with some videos and written information about a few topics that may interest young people. Find out more here: https://sfhearts.org.uk/support-services/youth-services/

Over the past year, I have seen 153 young people in 25 clinics across the South Wales and South West CHD Network, this is a mix of transition and young person clinics.

I have worked with 101 young people, aged 13-24 discussing issues around their congenital heart disease, treatment and procedure options, including supporting someone at a court hearing, speaking about mental health, jobs, diet, benefits, signposting, nudging them to call the clinical nurse specialist helpline for advice, and seeing inpatients in children and adult services.

The Bristol Heart Institute opened the Young People Room on Level 7 in May 2025. My role in this was to purchase and set up the technology (play station 5, appropriate games and TV). Speaking of tech, I still support Dolphin Ward (Bristol Royal Hospital for Children cardiology ward) and the Play team with their play station 5's. This was funded by a generous donation from the Bristol and Western Hospitals charity.

International travels - In July 2025, I was fortunate to take 4 young people on a week long trip to Finland alongside young people from Spain, Ireland, Iceland and another UK group. There was team building games, sea swimming, pool, sauna, lovely food, a trip into Helsinki to the paradox museum, a trip to a theme park. It was a wonderful trip, a write up for this can be found in Somerville Heart Foundation's Upbeat magazine online.

If you would like support for a young person with CHD as a primary heart condition aged 13-24, please get in touch via xander.patel-cook@uhbw.nhs.uk

Check out the new Network website pages:

Getting support for patients & families

Supporting our patients and their loved ones through their congenital heart condition and journey is very important to the Network.

On the newly refreshed 'getting support' patients and families pages you will find information on the range of support available to you. There are different services you can access, depending on how much support you need at a given time.

https://www.swswchd.co.uk/en/page/getting-support

- ✓ Helpful places to start
- ✓ When you want to find out more
- ✓ Referrals for psychology support
- ✓ Helpful reading for those living or supporting others with a heart condition

Plus:

- ✓ Wellbeing toolkits
- ✓ Wellbeing webinar series – living with a cardiac condition
- ✓ Psychologists' advice for managing cardiac surgery

Somerville Heart Foundation with Youth at Heart
For young people and adults born with a heart condition

We help you make informed choices, enable your voice to be heard, and listen to you

Youth SERVICES

For young people living with Congenital Heart Disease (CHD) and their families

WHO CAN BE REFERRED?

- ✓ Age 13-24
- ✓ CHD as a primary diagnosis
- ✓ Living in South West England or South Wales

HOW TO REFER

Young people can refer themselves for this service, as can family and healthcare professionals by emailing xander.patel-cook@sfhearts.org.uk

HOW WE CAN HELP

- ✓ Preparing for surgery/procedures
- ✓ Information, advice & guidance (non clinical)
- ✓ Lifestyle support
- ✓ Mental health, anxiety and low mood
- ✓ Transition/Transfer to adult services
- ✓ Support at the end of life

> Thank you for all the support over the last few years, you've helped me massively and I cannot thank you enough.
> GC, Young Person

☎ 07832 668907
https://sfhearts.org.uk/support-services/youth-services/

You can help with our vision to expand this service to other part of the UK. Thank You

Registered Charity Numbers: England and Wales 1138088 Scotland SC049673

Paediatric Intensive Care Support

Bristol Royal Hospital For Children

My name is Rachel Sanders, and I am one of a team of 11 sisters/charge nurses that work on Seahorse Paediatric Intensive Care Unit (PICU) at the Bristol Royal Hospital for Children (BRHC).

As the Level 1 specialist congenital heart disease surgical centre for the region, many children with congenital heart disease and their families may find themselves on PICU at some point in their patient journey. This may be as an emergency, but a large proportion will be elective (planned admissions).

We care for children on PICU from birth up to 18 years of age. You can expect to be nursed 1:1 by specialist PICU nurses and other allied health professionals, with around the clock medical care from a team of 15 consultants, as well as other medical professionals.

You may find yourselves on PICU after a cardiac catheter or after a cardiac surgical procedure. We can also look after children who require higher intensity observation or medication management. We then work closely with Dolphin Ward (the cardiac ward at BRHC), and the cardiology and cardiac surgical teams to provide ongoing cardiac care after your PICU stay.

Patient and Family Information Board

We, as a team, recognise how stressful this environment can be for parents and families, no matter how much you have been prepared through pre-admission clinics or antenatally. In an attempt to try and make things a bit easier, we decided to create an information board.

- What does the board display? This details what you can expect when you are here as an inpatient, and *some* of the equipment you may see or hear about during your stay. Some will not be relevant to children admitted with congenital heart disease, but much of it will be. It also provides an overview of some of the support options available to you whilst on the unit and some of the expectations of visitors and families, such as adhering to infection control rules.

- Where can the board be found? The information board is just inside the main doors of PICU at the BRHC – see photo below.

- Have you received any feedback? Families have fed back that they have found this information helpful, as PICU can be an overwhelming place with a lot of information to take in. We, as a team, are here to help, guide and support you and your child in any way we can whilst you are with us.

The information board was printed and funded by hospital charity, the Grand Appeal.

Useful Information

Visiting times and rules:

There is open visiting for parents. You will be given a green wristband to allow you access at any time. Siblings are welcome but they must be supervised at all times. We ask you to only have two visitors at the bedside at one time. There may be occasions when we must close the unit to visitors – we will try our best to inform you if this is going to happen.

We encourage you to have rest away from the unit and do not have facilities to enable parents to sleep on PICU. We may have some accommodation to offer you and can help with parking and CAZ exemption – please speak to the nurse in charge or ward clerk.

Please do not make phone calls at the bedside.
We have a zero-tolerance policy on aggression and abuse.

Infection control:

Please remove outdoor clothing and/or coats before entering the unit.

Please wash your hands at the bedside and use hand gel.

Please do not visit for at least 48 hours if you are unwell with diarrhoea and vomiting or until you feel well again with other illnesses. This applies to siblings and other visitors too.

Other services available:

There are a variety of services available to you while you are on PICU such as the LIAISE team, a dedicated play therapist, the chaplaincy team, psychology service and other charities that can support you. Please speak with your bedside nurse or the nurse in charge if you think you would like to speak with anyone, and they can make a referral. We also have access to a palliative care team who are available to speak to if required. There may be times when the organ donation team can help support families to think about organ donation and answer any questions that families may have.

There is a prayer room (The Sanctuary) available on Level 4 by Lighthouse Ward.

If you would like to keep a diary about your child's journey, please ask your bedside nurse how to access them. They are available online or as a paper version.

This is a teaching hospital so you may see a variety of student practitioners caring for your child while being supervised by their mentors. If you have any concerns, please raise these with the nurse in charge, consultant or the matron.

Sounds:

You may hear alarms and bleeps. Please do not be alarmed. These are to help us monitor your child.

DESIGNED AND FUNDED BY THE GRAND APPEAL BRISTOL CHILDREN'S HOSPITAL CHARITY

Bristol Royal Hospital For Children

Welcome to Seahorse Paediatric Intensive Care Unit (PICU)

Some of the equipment below may be used to monitor your child's condition during their stay on PICU.

Extra ventricular drain
Regulates pressure around the brain by draining any excess fluid if needed.

Cerebral function monitoring
This will monitor your child's brain activity if required.

Ventilator
Supplies oxygen and supports your child with their breathing.

Feed pump
Administers feed to your child via a pump through a tube.

Bedside monitor
Shows vital information about your child's heart rate, blood pressure, oxygen saturation and carbon dioxide elimination.

Syringe driver
Administers medications into the vein such as antibiotics, sedation and medications to support the heart.

Pacing box and wires
Small wires connected to the heart that allow us to assist your child's heart rhythm if needed.

Patient charting
Our unit is paperless, therefore, you may see staff using mobile devices. A computer system is used to record your child's observations, documentation, drug charts and care interventions.

Central lines
These are used to administer medications to your child.

Arterial lines
These are used to take blood tests from your child and to monitor their blood pressure.

Fluid pump
Administers fluids and other medications into the vein.

Bair hugger
This will warm up your child if required.

Emergency trolley
We use this to keep your child safe in certain situations - this is not just for emergencies.

Urinary catheter
A tube into the bladder to collect urine.

Cooling mattress
This will cool your child down if we are concerned about them becoming too hot.

Chest drain
A tube into the chest to collect any accumulated fluid or air.

Support
You are free to touch, comfort and talk to your child. It may help them to hear and recognise familiar voices, even if they don't appear to respond. You can also be involved in cares such as nappy changes and washes.

Medicines for Children

By Helen Barham PhD, MfC Medical Writer, Susie Gage, Lead Paediatric Cardiac Pharmacist, Bristol Royal Hospital for Children, and Chair of NPPG Cardiac SIG; Anna Rossiter, MfC Project Manager

Who is involved in Medicines for Children?

Medicines for Children is a joint project of the Royal College of Paediatrics and Child Health (RCPCH), the Neonatal and Paediatric Pharmacy Group (NPPG) and the children's charity Well Child.

NPPG
Neonatal & Paediatric Pharmacy Group

What is Medicines for Children?

- Medicines for Children (MfC) is an online resource that provides practical information, written in easily accessible language (medicinesforchildren.org.uk).
- For many medicines, patient information leaflets refer only to use in adults; the Medicines for Children leaflets provide a vital resource for parents and carers, written specifically about using medicines for children.
- The website hosts more than 200 leaflets on medicines and a wealth of supporting resources about medicines administration.
- Medicines for Children has also developed a medicines management app; to help parents and carers keep track of medicines administration (the current version is available on iOS iPhone only).

Collaboration between Neonatal and Paediatric Pharmacy Group (NPPG) Cardiac Special Interest Group (SIG) and Medicine for Children

Susie Gage set up and chairs the NPPG Cardiac Special Interest Group – a national group of paediatric cardiac pharmacists. The aim of the SIG is to share expertise and good practice nationally, to improve the care of paediatric cardiology patients.

The collaboration between the Cardiac SIG and Medicines for Children was prompted after a child was admitted to Bristol Royal Hospital for Children's intensive care unit with a high level of digoxin in their blood. This incident highlighted the lack of information nationally for parents giving digoxin to their children, including the signs of toxicity. Susie suggested that Medicines for Children should develop a leaflet on digoxin in children that would be available nationally, in particular, alerting parents to the signs of digoxin toxicity.

This leaflet opened up further discussions with Medicines for Children about involving specialist cardiac pharmacists in the development of medicines information leaflets. The NPPG Cardiac SIG has now developed thirteen new leaflets used for cardiac conditions and nine existing leaflets were reviewed. A poster with QR codes for 24 of the most common cardiac medicine leaflets is being developed.

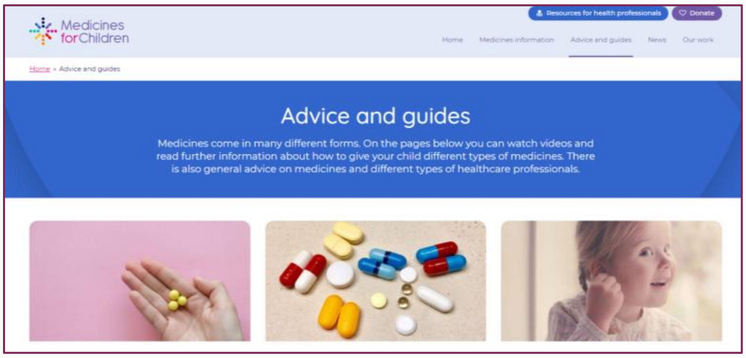
Specifically for our congenital heart disease (CHD) Network, Susie Gage and Clara Danielsen (Welsh paediatric cardiac pharmacist) worked with Medicines for Children to develop a leaflet about the use of rivaroxaban following Fontan completion surgery. This leaflet will be made available to parents, supporting patients and aiding healthcare professionals nationally.

Leaflets will be available via the Medicines for Children website. Parents/carers can be given a web link to this, or leaflets can be downloaded or printed out from the website directly.

How can you get involved?

Healthcare professionals - Medicines for Children is always keen to hear from healthcare professionals who would like to review or prepare leaflets. They provide CPD certificates to those who help.

Parents/carers/patients - They are also keen to hear from parents/carers and patients who would like to be involved – the patient voice is vital to what we all do.



Advice and guides

Medicines come in many different forms. On the pages below you can watch videos and read further information about how to give your child different types of medicines. There is also general advice on medicines and different types of healthcare professionals.

Also, if any healthcare professionals, parents/carers or patients would like to get involved with writing, reviewing or sharing their lived experience of cardiac medicines, please get in touch with the Medicines for Children team via medicines.leaflets@rcpch.ac.uk

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).

Thank you to those involved

ACHD Study Day, October 2025

We were delighted that 116 healthcare professionals representing services from across South Wales and the South West of England, attended the ACHD study day in October 2025. The majority of delegates were nurses and cardiac physiologists, as well as medics and Allied Health Professionals.

This annual study day has been running for 23 years and tends to focus on a different CHD condition each time. The theme this year was on Fontan circulation.

Huge congratulations to the team. Feedback was very positive, and the talk recordings are available on the Network NHS Future Platform.

> *"To see and hear the experiences our patients and families can face as they move across into adult CHD. It will enable us as paediatric nurses to support this process better." Paediatric nurse delegate*

> *"My approach to mental health issues and chatting to patients about their anxieties while having their echo will be improved by what I have learnt today. Thank you!" Cardiac Physiologist delegate*

District General Hospitals Level 3 Nurse Competencies

This development package to support level 3 nurses, particularly in their first year in post, as a CHD/ACHD nurse, has been revised, updated and relaunched this year. The competencies outline expected learning outcomes and support individual learning and local appraisal processes. The Network Lead Nurses offered to support centres in using this.

FutureNHS

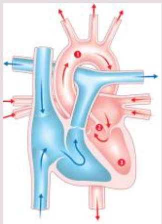
SWSW CHD Network NHS Future Platform

This platform for Network healthcare professionals' stores training and education resources, including many webinars from events. Contact the Network team if you haven't yet joined: CHDNetworkSWSW@uhbw.nhs.uk

Education is not the learning of facts, but the training of the mind to think – Albert Einstein

What's coming up in 2026?

- ☐ ECHO ACHD webinars, dates throughout the year – online
- ☐ Transition Study Event (focused on CHD) – Thursday 5th February 2026
- ☐ Paediatric Cardiology (PEC) Forum – Friday 6th February 2026
- ☐ Paediatric CHD Study Day – 25th February 2026



Children's Cardiac Nursing 1: Foundation Courses

Course overview

Aimed at nurses who are new to working within cardiac services, and more experienced nurses working within other areas that provide care for cardiac patients but not as a speciality.

This course focusses on cardiac anatomy and physiology of both the normal heart and the more common congenital cardiac lesions.

This course is open to nurses across the South Wales and South West CHD Network.

Dates:

January 25, February 8, 22, 29, March 14, 28 (Thursdays)

Or September 25, October 2, 9, 16, 23, November 13 (Wednesdays)

Bookings & Queries

FacultyOfChildrensNurseEducation@uhbw.nhs.uk

ACHD Echo Webinar Programme Update and Survey Highlights

By Gui Rego, Lead Healthcare Scientist in ACHD Echocardiography and Interim Education Lead in Echocardiography

The ACHD Echo webinar series has now surpassed 20 sessions, becoming a key educational resource for colleagues across the South West, South Wales, and beyond. With strong attendance, the programme has established itself as a consistent and accessible platform for advancing congenital echocardiography skills.

Recent survey feedback shows the impact this initiative is having across the Network. The series achieved an overall rating of 4.8/5, and attendees reported:

- ✓ Concrete improvements in day-to-day clinical practice.
- ✓ Better recognition of congenital lesions
- ✓ improved image optimisation and more structured reporting
- ✓ Greater confidence when faced with complex anatomy.
- ✓ Many colleagues have also used the webinar content to support local teaching, echo QA discussions, and multidisciplinary team (MDT) case reviews, extending the educational benefit directly into their departments.

The survey also confirmed the ongoing need for structured CHD training. Many indicated limited access to congenital patients, hands-on opportunities, or formal CHD teaching locally. This underscores the value of the webinar series and reinforces the need to continue expanding the educational offer.

Looking ahead, participants expressed strong interest in topics of morphological complexity, advanced ventricular function assessment, and emergency/ICU congenital echo. There was also clear enthusiasm for a hands-on congenital echo training weekend, focused on sequential imaging, supervised scanning, and case interpretation.

These insights will shape the way the webinars are being delivered, with a renewed focus on high-impact, clinically relevant sessions and the development of additional practical training opportunities.

Thank you to everyone who continues to support and engage with the series! Your feedback directly drives its evolution. If you haven't attended yet, we welcome you to join the upcoming sessions.

> *"A big thank you for running your monthly ACHD teaching sessions. I have found them all fantastic and a valuable source of information… you helped motivate me to finally start the accreditation process and I have recently passed the EACVI CHD exam... The support you give the 'CHD community' is really appreciated."*

British Society of Echocardiography

Swansea Echocardiographer Sheryl receives Lifetime Achievement Award

Sheryl Morris, Cardiorespiratory Echocardiographer, retired in autumn 2025 after over 40 years of NHS service.

Sheryl was also awarded the British Society of Echocardiography (BSE) Lifetime Achievement Award 2025. This award recognises Sheryl's dedication in her role in Swansea over these four decades, where she was instrumental in establishing the paediatric and congenital echocardiography service.

A BSE Lifetime Achievement Award is a fitting gesture to mark Sheryl's career. She has provided care to numerous children and families and trained many colleagues who have gone on to become cardiologists across the world.

Huge congratulations and happy retirement to Sheryl (pictured below, second left)

> *"Receiving the Lifetime Achievement Award was a total surprise. I have been fortunate to have had a career that I have thoroughly enjoyed – particularly echocardiography.*
>
> *I have a lot of people to thank over the years for getting me to this point – too many to mention here. I particularly want to thank all my colleagues who took the time to nominate me for this award as they thought I was deserving of it. I am truly overwhelmed and touched. Thank you so much. Diolch yn fawr!"*
>
> Sheryl Morris
> Retired Echocardiographer

Congratulations!

To Dr Stephanie Connaire, ACHD Consultant Cardiologist, in Cardiff

Dr Connaire joined the University Hospital of Wales (Cardiff) team in September 2025 and was actively involved in the Network strategy day and also presented at the autumn ACHD study day.

Current role and experience: Dr Connaire graduated from Cardiff University Medical School in 2015. She trained in hospitals across the Oxford region, Bristol and South Wales. She completed subspecialty training with the ACHD teams in the Bristol Heart Institute and University Hospital of Wales.

Particular areas of interest and expertise: Dr Connaire is interested in all aspects of Adult Congenital Heart Disease and Maternal Cardiology. She also has expertise in cardiac imaging with accreditation in transthoracic and transoesophageal echocardiography, and a particular interest in intra-procedural imaging.

Outside of work, Dr Connaire likes to keep active and is a very keen runner. She has run several marathons and regularly races competitively for her Cardiff-based running club.

As part of the South Wales and South West CHD Network, Dr Connaire also spends time in Bristol, runs visiting clinics in South Wales, and contributes to the on-call service for patients across the region.

Welcome to Dr Silvia Caroli Consultant Paediatric Cardiologist in Bristol

Dr Caroli joined the team at the Bristol Royal Hospital for Children in September 2025. She is particularly interested in advanced echocardiography, medical education, and transition.

She has dual training in paediatric cardiology and Adult Congenital Heart Disease and has previously worked as a Paediatric Cardiology Consultant and ACHD Consultant at Royal Brompton Hospital and Leeds Teaching Hospitals.

Outside of work, Dr Caroli enjoys performing arts (theatre, musicals, opera, live music) and horse riding.

Christmas choir for children with CHD

Ready for Christmas, a choir composed of children who have bravely faced heart surgery, alongside the friends and family of a talented young band, came together to create something special.

They recorded a beautiful Welsh Christmas song "Pob Un Plentyn" ("Every Child"), that was released in December 2025.

The choir, known as "Cân o'r Galon" ("Song from the Heart"), was formed to celebrate the courage of these children, and foster a sense of community and support for children and families in West Wales navigating the challenges of living with Congenital Heart Disease.

The song was composed by one of our Network local paediatricians with expertise in cardiology, Dr Sian Jenkins at Glangwilli Hospital, and performed by the children together with young band "Coron Moron."

To watch this, visit: https://www.youtube.com/watch?v=IkVEUJq2hq8

The hope is that this project will help to support local children and families affected by Congenital Heart Disease and raise funds, and awareness about the conditions and challenges they face.

Network update

By Michelle Jarvis, CHD Network Manager

As highlighted throughout this newsletter, there has been a wealth of fantastic work across the regions this year. This includes excellent training and education opportunities, as well as a refreshed Network education strategy. The calendar for next year is already filling up with exciting events, so be sure to check out what's coming up in 2026 (p.6)

The Network team were very impressed following our visits to the Level 1 paediatric and adult services (Bristol) and the Level 2 adult service (Cardiff) for a review of their self assessment against the national NHS England congenital heart disease standards. There were some excellent service updates and areas of good practice to highlight. The Bristol ACHD service has a strong national reputation for innovative interventions, highly specialised surgical procedures, and obstetric cardiology alongside expertise across pulmonary hypertension, ICC, and end-of-life care. The Bristol paediatric service continue to achieve consistently strong surgical and interventional outcomes whilst also delivering novel cath lab interventions.

The Cardiff ACHD service reflects a cohesive, supportive team built on a highly experienced workforce, with a clear strategy for psychology, cardiac rehabilitation provision for patients and an established obstetric cardiology service meeting all national standards. We look forward to meeting the Cardiff paediatric cardiology team for their upcoming assessment, which will mark the conclusion of this review cycle.

As has been the case with all the of assessment reviews that have taken place over the past 18 months, the service teams have developed action plans to tackle key challenges and to improve compliance against the standards. All of the CHD services at sites across the Network should be commended for their ongoing commitment to ensure they deliver equitable, high-quality care to CHD patients of all ages.

Suggested projects, addressing the challenges identified during the recent reviews and the Level 1 & Level 2 strategy day workshops have now been incorporated into the Network workplan. Through this work, we aim to continue supporting CHD services across our regions in progressing 'Beyond Compliance' with national standards, aligned with our refreshed Network strategy and vision for the next 5-10 years.

Network dates for your diary!

Key Network meetings:

Thursday 26th February 2026:
Network Board and M&M

Thursday 21st May 2026

Network Board and Clinical Governance

Staff Photographic Competition #8: 'November scenes across the Network'

Throughout November 2025 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.swswchd.co.uk/en/page/photographic-competition

Winner

The winner is 'swans at sunset, Portishead Marina'- photographed by Rachel Wyatt, ACHD Clinical Nurse Specialist

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 CHDNetworkSWSW@uhbw.nhs.uk

In the spotlight:
Gloucester Royal Hospital CHD Services

Photo above: David Withers with cardiology ward Sister Tash, promoting the Network newsletters

Some of the Network team visited the CHD teams in Gloucester. This was a fantastic opportunity to celebrate the good work being done by the teams and see what support we could offer them. The Network team were particularly keen to celebrate and highlight the enthusiasm and hard work of David Withers (ACHD Specialist Nurse), who has shown incredible tenacity, fighting hard to establish the nursing role for the adult service in Gloucester; advocating for his patients, and streamlining the care provided for them.

David Withers shared: The recent visit from the Network Manager (Michelle Jarvis) and Lead Nurse (Becky Lambert), marked an important milestone for congenital heart services in Gloucester. The visit provided an invaluable opportunity for them to meet face-to-face with the nursing Matron (Lisa Harvey), the Adult CHD Cardiologist (Dr David Lindsay), both Consultant Paediatrians with Expertise in Cardiology (Dr Pradeesh Mappa and Dr Matthew Beake) and myself.

The meeting gave everyone the chance to discuss each other's services and priorities. This discussion included how to strengthen the transition pathway, and whether a joint paediatric–adult transition clinic could be developed to provide a smoother, more integrated experience for young people moving into adult care.

Positive news!
Notably, following this visit and discussions, the Gloucester ACHD specialist nurse role became substantive.

The Network team were also shown the clinic areas, allowing them to see where the ACHD patients are assessed and supported. The meeting has helped to move several important workstreams forward.

Overall, it was a constructive and positive visit, which strengthened relationships and set foundations for future collaborative working. The Network team hope to make more visits to centres across the Network in the future.

← Photo: Dr Pradeesh Mappa (left) & Dr Matthew Beake (right), Consultant Paediatricians with Expertise in Cardiology

Photo above from left to right: Lisa Harvey, Matron; Becky Lambert, Network Lead Nurse; Dr David Lindsay, ACHD Consultant Cardiologist; Michelle Jarvis, Network Manager; David Withers, Specialist Nurse

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

My name is Debbie, and I was born in 1966. Shortly after birth, I was taken from my local hospital in Swansea to Great Ormond Street Hospital in London. I travelled to London via an incubator on a train to Paddington. I was then diagnosed with the Transposition of the Great Arteries (known as TGA). I underwent a septostomy at 6 weeks old.

In 1971 at the age of 5 when it was decided that I was strong enough to undergo surgery, I had a Mustard operation which was carried out by Mr Jaroslav Stark and his team, again at Great Ormond Street Hospital. As part of the Mustard operation baffles are made in the heart to re-direct the blood flow to the appropriate blood vessels.

Until the age of 28, I lived a normal life in Wales, apart from annual check-ups and tests at the National Heart Hospital and Brompton Hospital, both in London.

In 1995 at the age of 28, I had a balloon angioplasty at the Brompton Hospital London, under the care of Professor Jane Somerville, who is also the founder of the national charity Somerville Heart Foundation.

In 1996 with the help of specialist care, my daughter was born in Chelsea and Westminster Hospital. In 2010, I had an Amplatzer device fitted to help a leak in the baffle which had caused TIA's.

In February 2013, I suffered my first episode of arrhythmia for which I initially had a cardioversion and then a few weeks later I had an ablation. Unfortunately, the arrhythmia returned in August 2013 which meant undergoing a second ablation.

I had various tests and check-ups during the next few years but in June 2022 after feeling unwell, I was admitted to hospital with fluid on the lungs. I was later admitted to Brompton Hospital and underwent an initial transplant assessment with further tests at Harefield Hospital. After tests, I was then placed on the transplant list in January 2024.

In July 2024 I was transferred from Harefield Hospital to the Freeman Hospital in Newcastle and placed on the transplant list but under their care. I was fitted with an ICD and remained on the transplant list. I was contacted to attend by the transplant coordinator at the Freeman in September 2025 as a potential donor had been found, but sadly after being prepared for theatre, the surgery was unable to go ahead.

I always knew I would need life-long follow up for my heart condition. It has been a tough journey at times, but overall, it has been a good experience, and I have had and continue to have the most amazing care at each hospital I have attended.

Over the many years my local team in Swansea and Cardiff have helped and looked after me plus acting as a go-between with Harefield and the Freeman, co-ordinating my medical care. This includes everyone from Dr Dirk Wilson (Consultant Cardiologist), Dr Helen Wallis (ACHD Consultant Cardiologist), Kindre Morgan (Clinical Nurse Specialist) and all the liaison nurses. Also, Dr Anna McCulloch (Clinical Psychologist) who has helped me look at bad times in a different light. I praise them all for their support.

I am very grateful for the support of the South Wales psychology service. I don't recognise myself as the person who met with Dr McCulloch initially compared to how I am now. She helped bring out the confidence in me, which I am so happy about. Having a congenital heart condition can be isolating as it's a hidden condition, and thanks to the Somerville Heart Foundation Conference in Bristol, I enjoyed meeting others with the same CHD defect as me.

Somerville Heart Foundation is a UK-wide charity dedicated to supporting young people and adults born with CHD. They provide support, advocacy, communication, and a community for those they are here to help.

South Wales and South West
Congenital Heart Disease Network

Find out more at: **http://www.swswchd.co.uk**
Follow us on **@CHDNetworkSWSW**

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 2026, 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.

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