

Newsletter



Updates from
your CHD Network

Inside this edition

- Clinical Director's Introduction...2
- Life in West Wales...3
- New Clinical Updates...4
- Heart Heroes Family Support Worker...5
- BCCA Annual Conference...6
- Fetal Cardiology...7
- Paediatric Cardiac Nurse Education...8
- Welcome and Staff Changes...9
- Network Manager Update...10
- National Network of CHD Networks...11
- Learning Difficulties and Support...12
- Staff Photo Competition...14
- Bethan's Patient Story...15
- Useful Contacts...16





Introduction from our Clinical Director Dr Stephanie Curtis

Welcome to the Winter 2023 edition of the South Wales and South West Congenital Heart Disease Network newsletter!

As the year draws to a close, we are proud to present our latest Network newsletter. Many thanks again to Rachel for pulling all these articles together. It seems that we have an endless flow of positive stories from throughout the region, which fills me with hope for the future! As always, we struggle against a lack of funding to provide our services, but continue to work with our patients, families and charities to advocate for congenital heart disease across South Wales and the South West of England.

In this newsletter we can see that strong local teams provide patients with expertise and support closer to home. Often patients can find a journey to a specialist centre time-consuming and expensive, which is why care in local communities is so vital. It is wonderful to see the local teams thriving in West Wales and new staff members joining us across the region.

We share some of the progress we have made in practical terms in the areas of image sharing between England and Wales and the creation of a new ACHD consultant discussion forum, similar to the paediatricians with expertise in cardiology (PEC) group. In 2023 we notably held the South Wales self-assessment visits to provide our peripheral hospitals with support for patient care in line with the NHS England Congenital Heart Disease Standards. Thank you to the adult and paediatric Welsh teams for all their hard work, engagement and collaboration with this process. We are planning to invite the South West peripheral hospital CHD teams to follow this important audit process in 2024. Our education programme has always been one of our strengths and continues for doctors, nurses and allied health professionals at all levels.

In November 2023, we hosted the National Networks of CHD Networks Annual Meeting in Bristol, after a successful British Congenital Cardiology Conference. CHD Network teams from throughout the UK were able to catch up with colleagues and share ideas and solutions to the common problems we all face.

It leaves me only to wish healthcare professionals, our charitable support groups, patients, families, and carers a very Merry Christmas, Happy new Year and a healthy 2024!

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

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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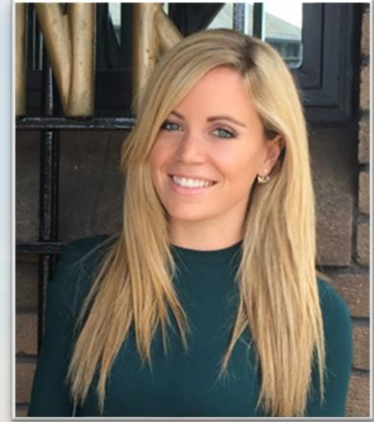
In the spotlight: Life in West Wales

By Beth Shiers, ACHD Clinical Nurse Specialist

My name is Beth, and I am an Adult Congenital Heart Disease Clinical Nurse Specialist (ACHD CNS). I work as part of a wider team of fantastic CNS's that cover South Wales.

A little background

I have worked as an ACHD CNS for over 12 years now and I really enjoy my role. I previously worked as an ACHD CNS in our specialist surgical ACHD centre in Bristol which gave me an invaluable experience in providing holistic care for patients with ACHD.



The 'hub' for our South Wales ACHD service is in Cardiff. During COVID-19, I had a little boy and my family relocated to West Wales. I now cover the West Wales ACHD Clinics in Carmarthen and Withybush. These clinics are run under the expert care of our lead ACHD Consultant, Dr Helen Wallis, and we maintain a close relationship with the ACHD team in Cardiff and Bristol.

Team photo (left) with Health Care Assistant Caroline, ACHD Clinical Nurse Specialist Beth, Physiologist Rebecca and Dr Helen Wallis, ACHD Consultant

Offering patient care closer to home

I offer nurse led support to the ACHD patients in the West Wales region. It has been really rewarding to be able to offer support and follow up for patients closer to their homes (especially those in rural and remote areas!) and during inpatient stays. I have received lovely feedback from patients who have appreciated not having to travel as far for support.

Raising awareness of ACHD

Part of my role is promoting the awareness of ACHD, and I have been building relationships with other allied professionals and offering education sessions across the Hywel Dda Healthboard.

Recruiting ACHD Champions/Link Nurses

As an ACHD service we are keen to recruit ACHD Champions/link nurses in each health board to help educate and empower nurses to care for patients with ACHD. If you are interested in this role, please get in touch: achdnurse.cav@wales.nhs.uk

I feel extremely lucky to be able to work in my role as CNS and to live in such a beautiful part of the world. I look forward to continuing to offer this support for our West Walian ACHD patients closer to home.





What's new: clinical updates

By Dr Stephanie Curtis, CHD Network Clinical Director and ACHD Consultant



Breakthrough: Update on Image Sharing

Image sharing between England and Wales has always been a thorny problem for us as a Network. Up to now, echoes have had to be shared remotely or copied onto discs and sent to Bristol, resulting in delays and thus patient safety issues. We have faced IT, governance and cyber security challenges to overcome this hurdle and the process has been complex and arduous.



However, I am delighted to be able to say that we now have successful links between Bristol and the hospitals in the Health Boards of Swansea Bay and Aneurin Bevan. We are now working with Cwm Taf Morgannwg and Hywel Dda Health Boards and hope to achieve this by the end of the year.

The means that any of our clinical team can view echoes performed in Wales directly on a browser in Bristol. Stephen Morris, PACS Manager in Swansea Bay has been instrumental in making this happen so thank you, Stephen!

New Endocarditis Guidelines



At the European Society of Cardiology Annual Conference in Amsterdam in August 2023, new guidelines were presented on infective endocarditis.

Endocarditis is always a hot topic in congenital heart disease as many of our patients have artificial valves or material in the heart that increases their risk of infection.

The guidelines re-iterates the importance of excellent dental hygiene and skin care to avoid endocarditis. Antibiotic prophylaxis continues to be recommended for many of our patients, as with the previous guidelines, with the strength of recommendation moving from Class IIa to Class I. The preventative antibiotics needed prior to high-risk dental work have confused some over recent years; the new guidelines have changed a little for children and adults and provide welcome clarity on this subject.

The authors emphasise the importance of the endocarditis team, comprising cardiologists, surgeons and microbiologists, as well as the early and more frequent use of transoesophageal echocardiography, and the importance of CT PET scanning in prosthetic valve endocarditis.

Many of us will be relieved to hear that some patients with straightforward disease caused by certain organisms can be switched to outpatient antibiotic treatment after only ten days of iv antibiotics.

Find out more at: [ESC Guidelines & Scientific Documents \(escardio.org\)](https://www.escardio.org)



Project Award Nomination:

Percutaneous therapy for superior sinus venous defect

Congratulations to Dr Radwa Bedair, ACHD Consultant, and her team at the Bristol Heart Institute for receiving a nomination for innovation and improvement in the 2023 NHS Recognising Success Awards.

This was for the innovating and pioneering work in introducing the percutaneous therapy for superior sinus venous defect. An amazing achievement - well done to those involved! More to follow!



Medicines for Children have created a QR code information poster about medicines used to treat heart conditions.

Healthcare professionals may like to display these in their wards/clinic settings.

[Medicines-for-heart-conditions.pdf](https://www.medicinesforchildren.org.uk/medicines-for-heart-conditions.pdf)
([medicinesforchildren.org.uk](https://www.medicinesforchildren.org.uk))

Medicines for Children Information about medicines used to treat heart conditions

Medicines for Children provides practical and reliable information about more than 220 medicines used for children and young people. The information addresses frequently asked questions, such as how and when to give the medicine, what to do if you forget to give the medicine, and any possible side-effects. The website hosts many other useful resources and regular news stories.

Medicines for Children home page

 Amiodarone for abnormal heart rhythms	 Amiodipine for high blood pressure	 Aspirin for prevention of blood clots	 Atenolol for high blood pressure	 Clopidogrel for heart failure
 Carvedilol for heart failure	 Chlorthalidone for high blood pressure and heart failure	 Enalapril for high blood pressure	 Enoximone for pulmonary hypertension	 Flecainide for abnormal heart rhythms
 Furosemide for heart failure and pulmonary oedema	 Labetalol for high blood pressure	 Lisinopril for high blood pressure	 Ramipril for high blood pressure	 Sildenafil for pulmonary hypertension
 Spiramycin for heart failure	 Warfarin for prevention and treatment of blood clots	<p>How to use QR codes</p> <ul style="list-style-type: none"> Scan the QR code using either your phone camera or a QR scanner app (which you can download from an app store). Click or tap on the icon or website bar that appears, which will take you to the right page on the website. You can read the information or download it onto your phone. 		

Medicines for Children is a project funded by the registered charity Royal College of Paediatrics and Child Health (RCPCH), charity: 1077246), the Neonatal and Paediatric Pharmacists Group (NPPG) and WellChild.



New ACHD 'Gang' Meetings

Just a few years behind the 'PECs' (Paediatricians with Expertise in Cardiology), we have formed a new group for Level 3 ACHD consultants. This was designed to be a virtual forum where we can discuss issues that affect us all and hopefully come up with some solutions. So far topics have included backlogs, databases, workforce planning, physiologist led clinics, CPD, teaching and training. There have been two meetings so far and the plan is to meet quarterly.

Feedback from Dr Catherine Blakemore, Consultant Cardiologist, Torbay and South Devon NHS Foundation Trust.

"It's a great idea to get us all together to share our experiences of managing Adult Congenital Heart Disease in peripheral hospitals. It's really useful to have a forum where we can share ideas and try to solve problems together."

Pioneering Heart Heroes Family Support Worker role



In collaboration with the Heart Heroes charity and the Bristol Royal Hospital for Children (BRHC), a new Family Support worker post was launched in April 2023.

Nicola offers emotional and practical support for families whose children are undergoing surgery and care on Dolphin (cardiac) Ward at BRHC. As a heart Mum, Nicola understands the challenges that families face so please do feel free to stop and chat if you are on the ward and see her.

Zoe, the Dolphin Ward Sister at BRHC shared a little background to the role:

"This role has been created from cardiac family and service user feedback and is being supported by the charity Heart Heroes. As a cardiac ward and service, we have already built up a great relationship with Heart Heroes and by developing this role we will be able to provide a continued level of support to families from home to hospital. Heart Heroes provide fantastic support to children and families who have been affected by Congenital Heart Disease across the South West and are a really positive champion for the cardiac service provided here. The opportunity to build this role together is exciting and I'm sure will continue to evolve with time."

Contact details and visiting times for Nicola are available on Dolphin Ward, BRHC. Thank you to Nicola, and everyone who has supported the development of this role. Your help and expertise has been really appreciated.



To find out more about Heart Heroes and the Network's other Charity and Support Groups, please visit the Network website: www.swswchd.co.uk/en/page/charities

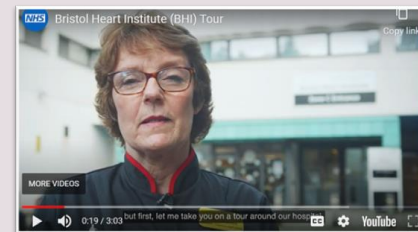
National Experience of Care Week 2023

Did you know.... Two of our CHD Network videos were chosen to feature in the NHS England National Experience of Care Week 2023.

1. Louis' patient story on how musical therapy supports our CHD patients.



2. The Bristol Heart Institute virtual tour film to support young people with CHD transferring from paediatric to adult services.



Both of these films are available to view on our Network website:

www.swswchd.co.uk

The national experience of care week initiative showcases films that demonstrate how we understand and improve experience of care, by working together with our communities.

This year's theme followed experience 'through the life-course', ranging from birth to end-of life. As a Network, we provide care for all ages and at significant moments through life.

You can find all the inspiring videos in one place here on the YouTube channel. [Experience of Care Week 2023 - YouTube.](#)



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.swswhd.co.uk).



The British Congenital Cardiac Association Annual Conference was successfully held in Bristol, in mid-November 2023.



This two-day face-to-face conference with over 400 delegates from across the country, as well as some international attendees, provided an excellent opportunity to Network and share learning.



The supporting workstreams were led by the Paediatricians with Expertise in Cardiology Specialist Interest Group (PECSIG), the Congenital Cardiac Nurses Association, the British Adult Congenital Cardiac Nurses Association, the Congenital Cardiac Anaesthesia Network, and the Physiologists.

The conference dinner was hosted by Dr Katy Huxstep, PEC in Truro, and was held at the Bristol Museum and Art Gallery. Thomas Morris, author of the 'The Matter of the Heart: A History of the Heart in Eleven Operations' was the guest speaker.

Thank you to all those involved in organising, presenting and attending this fantastic event!



The return of the South West and South Wales Advanced ACHD Training Programme

The ACHD advanced training programme was restarted in April 2023, after a hiatus for COVID-19. The complete programme runs over three separate days and the cycle commenced again on 25 April 2023 with the theme 'BASIC ACHD.' This was delivered online and proved popular with over 80 delegates from around the region and beyond.

This teaching programme is aimed at cardiologists with an interest in ACHD and cardiologists in training, as well as specialised allied health professionals.

The ACHD cardiology faculty from Bristol, Cardiff (and Genoa!) taught on topics such as coarctation, bicuspid aortic valves, pregnancy, emergencies, and long term outcomes in tetralogy of Fallot.

Feedback was very positive, as always, with delegates commenting, "all presentations were excellent", "good coverage of the spectrum of ACHD", "all the talks were really relevant and interesting."

The next day (Intermediate ACHD) will be in April 2024 and include topics such as Ebstein's anomaly, transposition of the great arteries and anomalous coronary arteries.

We are delighted that Dr Victoria North, new substantive ACHD Consultant at the Bristol Heart Institute, is going to be taking over the leadership of this advanced ACHD training programme.

Dr Victoria North has a lot of experience and expertise in teaching, as well as much enthusiasm!





Fetal Cardiology Study Day

By Angie Smith, Fetal cardiac and midwife sonographer

Friday 6th October 2023 saw Bristol Children’s Hospital successfully host its third fetal cardiology study day, led by Dr Patricia Caldas, paediatric and fetal cardiologist and sponsored by Canon Medical systems.

60 delegates made up of fetal medicine specialists, sonographers, trainees and paediatricians, attending both in person and virtually, came from all over the South West, and we even had a group from Iceland travel to join us.

The Bristol team along with colleagues from Cardiff University Hospitals Wales and the Evelina hospital in London presented a packed day, sharing their knowledge of fetal cardiology.

The day was very well received with comments such as:

“A really informative day’

“This has really helped with my cardiac knowledge’

‘Absolutely tremendous talks’

The success of the CHD Network and its positive impact was the inspiration for the creation of this course, and the fetal cardiology team continues to provide support and education for the region.

This includes a new monthly teaching session for the Royal Cornwall Hospital, with the objective of increasing training opportunities and confidence in scanning the fetal heart for sonographers performing the 20-week anomaly scan.



Fetal Cardiology webinar series

The fetal cardiology team have also embraced new ways of working with a fetal cardiology webinar series.

The webinar series is still available on the South Wales and South West CHD Network NHS Future Platform!

Network healthcare professionals can register for this by emailing: SWalesSWCHD-manager@future.nhs.uk



SWSW CHD Network NHS Future Platform

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

- + Fetal cardiology webinar series
- + Paediatric cardiology nursing webinar series
- + Paediatrician with Expertise in Cardiology (PEC) platform
- + Psychology webinars
- + ACHD study day webinars & resources
- + Physiology platform (*currently under development*)

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



Paediatric Cardiac Nurse Education

By Alison Wood, Cardiac Educator, BRHC

It has been a busy year for paediatric nurse education with two foundation cardiac courses, an enhanced level cardiac nursing module and a regional study day being delivered face-to-face in Bristol. This takes a huge amount of coordination of the teaching spaces, speakers, attendees and online learning resources. The administrators within the team are brilliant at ensuring the events run smoothly.

The foundation course was well attended by nurses from BRHC working within the cardiac speciality, but also by nurses working in regional hospitals and the community who care for children with congenital heart disease alongside a wider workload. The course has great feedback with all participants agreeing that they had enjoyed the course, and that it had improved their knowledge and influenced practice.

The more challenging enhanced course has so far only been available to nurses working on the cardiac ward and paediatric intensive care in Bristol, but a wider audience may be considered in the future. As well as investigating some of the rarer cardiac conditions, this course encourages nurses to think about why they do what they do in clinical practice.

The regional study day accommodated nurses from across the Southwest region. The adult teams have been sharing their knowledge hosting study days for 20 years, and within paediatrics there is an equal need for these events. Again, the feedback was fantastic with some tips that we can implement to make it even better next year. The parent speaker who presented virtually, is not only a heart patient herself, but also has a child with congenital heart disease. The nurses attending really valued hearing about family perspectives and the impact on their lives.

All future study events are advertised on the CHD Network website and please get in touch if you are interested. FacultyOfChildrensNurseEducation@uhbw.nhs.uk

Amazing course. My cardiac knowledge has dramatically improved, and I can take this experience and share with colleagues. I would recommend to anyone who wanted to improve or gain knowledge in cardiac conditions.

Foundation course member

What I have learnt on this course will help me to provide care to my patients with a better understanding of their conditions. I feel a lot more confident and competent in looking after cardiac patients.

Foundation course member



Coming up in 2024!

Children's Cardiac Nursing 1: Foundation Courses

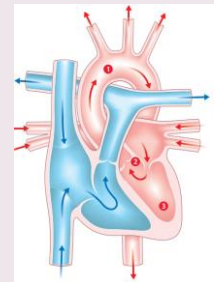
January & September 2024

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)

Paediatric Cardiac Study Day

26th February 2024, Bristol

Bookings & Queries

FacultyOfChildrensNurseEducation@uhbw.nhs.uk



Welcome



Update on team changes

Welcome to the Network Nicola Parish, Clinical Psychologist for the South Wales Paediatric Cardiology Service, who joined the team in May 2023. Also, to **Gayle McKerracher**, new Clinical Lead in paediatric psychology at the Royal Cornwall Hospital.

Congratulations also to **Dr Jennifer Shortland** in her recent appointment as Consultant Cardiologist specialising in electrophysiology and inherited cardiac conditions at Bristol Royal Hospital for Children. Dr Shortland also runs some clinics with the team in Cardiff.

Welcome to **Laura McCarthy**, new part-time cardiac Transition Nurse Specialist in Cardiff.

We would also like to welcome **Dr Justin Thuraisingham**, new Consultant Paediatrician with Expertise in Cardiology (PEC) in Exeter, and **Dr Muhammad Shahjehan**, new PEC in Plymouth.

At Musgrove Park Hospital, we welcome **Deirdre Molloy**, new Services Manager covering adult CHD..

We bid farewell to **Rosalie Davies**, General Manager at BRHC who left in June 2023, and congratulate **Ed Roberts** on taking over the baton for this role. We also welcome **Megan O'Brien**, as Assistant General Manager.

We also said farewell to **Marta Cunha**, ACHD Clinical Nurse Specialist at the Bristol Heart Institute and welcomed **Soji Daniel** and **Danielle McPeake** to this team.

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



Introducing Grace

Children's Cardiac Transition Nurse in Exeter

Hi, my name is Grace and I have recently started a new role as a Children's Cardiac Transition Nurse in Exeter 1 day a week.

I am really excited about this role and am looking forward to setting up clinics with young people who will be transitioning from children to adult cardiology services.

My role will involve supporting young people and their families through the transition process, making sure young people understand their hearts and helping them to become more independent with their healthcare.



Alongside this, I also work on the Neonatal Unit in Exeter, caring for premature and sick babies. My background was in Neonatal Intensive Care in Norwich, Norfolk and Paediatric Intensive Care at the Evelina Children's Hospital in London. This was where my interest in cardiac nursing began as I cared for infants, children and young people pre- and post-operatively following congenital cardiac surgeries.



My partner and I moved to Exeter from London a year and a half ago, and we are loving it. We live close to Dartmoor, and we love going for long walks and wild camping. This summer I have been getting braver at swimming in the sea, which I am loving.

In my free time I mostly have my nose stuck in a book, and sometimes I play the bass guitar pretty badly. I look forward to being a part of the Network and meeting more patients, families and colleagues in the world of congenital heart disease!

Dr. Idoia Grange Sobe

Locum Consultant Paediatric Cardiologist at Bristol Royal Hospital for Children

Dr. Grange is passionate about congenital heart disease from the early days to the elderly years. She has a special interest in adolescents and women's health. Dr. Grange has also dedicated part of her training to congenital cardiac imaging.



To find out more about Dr Grange Sobe, visit her profile page on the Network website www.swschd.co.uk/en/staff/167



Network update

By Louise Hudson, Network Manager (until October 2023)

When the Spring 2023 newsletter was published, the CHD Network team had refreshed its workplan and was springing into action with new projects and reinvigorating longstanding programmes of work. With winter upon us it's positive to see seeds sown earlier bearing fruit.

South Wales CHD Standards Self-Assessments

One area of focus, following the delivery of the CHD National Standards Self-Assessment Report (Welsh Level 3 Centres) to the Welsh Health Specialised Services Committee (WHSSC) in December 2022, was a review of this year's action plans with four Health Boards covering South Wales.

Collaboration with the Cardiac Network for Wales, our Level 2 centre in Cardiff and the commitment of our local centres and Health Boards to the process, has driven improvement and highlighted where further change is needed to provide equitable care in this part of the Network's geography. As we look forward to 2024, the next phase of self-assessment will see the team working closely with centres across the South West.

Strong collaboration

Other projects reaping results from strong collaboration have focussed on the transfer of patient images between Wales and England and the flow of patient information across the Network. Changes in processes and documentation have yielded positive feedback and are making a real difference behind the scenes to patient care.

Transition

Transition of patients from paediatric to adult services remains a focus. More young people are now receiving support in transition clinics and through identified nursing support. These approaches facilitate engagement with young people on a range of important issues that influence their interaction with adult services and their health outcomes later in life. Nurses delivering these services shared experiences and good practice via the Network's recent Transition Study Day, bringing learning back into their work with young people.

Patient involvement

Broadening patient involvement, supported by experienced representatives, clinicians and the team is another focal point this year. Some of our patients' stories took centre-stage at the national events hosted in Bristol in November, helping influence change in services locally and beyond.

Thank you to Louise for all her hard work and support to the Network.

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

Meet Michelle, our new Network Manager



Following an extremely competitive recruitment process, we were delighted to welcome Michelle (pictured above) to the team in November 2023 as our new CHD Network Manager for South Wales and the South West.

Michelle joins us with 20 years of experience in the NHS including over 10 years working as an operational manager in front door services at the Bristol Royal Infirmary, alongside more recent work in acute Trust commissioning and contracting at University Hospitals Bristol and Weston.

"I am very excited to have joined the South Wales and South West CHD Network team. I am very much looking forward to getting to know and working together with all partners across the Network to help contribute to the overall aim of providing high quality, equitable care for all CHD patients."

Find out more about Michelle on our website: www.swswhd.co.uk/en/page/who-we-are

Network dates for your diary!

Key Network meetings:

23 January 2024: Network Board & Network M&M

18 April 2024: Network Board



National Network of CHD Networks Annual Meeting, November 2023

We were delighted to host the National Network of CHD Networks Annual Meeting in Bristol this year. This face-to-face meeting was held the day after, and in the same venue, as the British Congenital Cardiac Association (BCCA) conference.

We welcomed 67 attendees from around the country, representing the NHS England CHD Clinical Reference Group including patient representatives, CHD Network Leads, and NHS England Leads and Commissioners. We were grateful to Nicola for providing a Heart Heroes charity promo stand and to Janssen for generously sponsoring this event.

As patients are at the heart of what we do, the national event opened with Bethan's patient story (see page 15). The programme provided an opportunity to receive key national updates, gain insight of how other Networks function, share ideas, successes and challenges, and learn from each other. As well as highlighting developments in workforce and research, attendees participated in discussions and considered solutions to contribute to better patient outcomes.

Excellent energy and engagement in the room all day, positive contributions, and suggestions from all around the country.

Well-arranged agenda, great chairing, focus on solutions rather than problems, high energy and welcoming atmosphere. Thank you!

I thought all the speakers were engaging and delivered clear presentations. I enjoyed the group work / conversations and the shared learning from these.





Disabilities and Learning Disabilities with Congenital Heart Disease

By Martyn Wood, Paediatric Disability Clinical Specialist, Bristol Royal Hospital for Children

Aren't acronyms great? Instead of having to say congenital heart disease every time, you can just say CHD. But if your background is in adult nursing maybe you would think coronary heart disease. It is the same with my role. When you see ASD, you probably think atrial septal defect, but to me it stands for autistic spectrum disorder – context is everything.

There is a significant overlap between CHD and learning disability. One in a hundred children have CHD, one in seven hundred children have Down's Syndrome (other learning disabilities are available!) and 40% of children with Down's syndrome also have CHD.

Research shows that children with CHD show more difficulties with social interaction and communication, like characteristics of autistic spectrum disorder. This may be caused by long hospital admissions, missing school, and not seeing friends. There is also a link between CHD and autistic spectrum disorder.



Support for children

Children's wards are generally pretty good at providing for the additional needs of children with learning disabilities. There are play specialists, sensory toys and an innate expectation that parents are involved in all aspects of their child's care.

The nurses on the ward use resources like the [hospital passport](#) to better understand their patients' needs and alerts on the electronic patient record highlight those patients with a diagnosed learning disability or a hospital passport, meaning that **reasonable adjustments or support can be offered even in advance of admission**. These alerts are added manually so it's probably worth checking it has been done if this applies to you.

Transition from paediatric to adult services

The hospital passport is also a useful thing to have at transition. We encourage parents to update the passport with their child before their transition appointments, then it can be shared with the adult learning disability (LD) team who cover the BHI (Bristol Heart Institute).

The adult learning disabilities team will support patients and their carers, with the changes that come with adulthood – the change to mental capacity assessment for procedures rather than parental consent. This should be discussed within the transition process and should not come as a surprise on the first visit to an adult hospital. Please note that this assistance can only be offered when the patient is known to the paediatric disability team. Recording for example Down's Syndrome as a diagnosis on every clinic letter and discharge summary doesn't make this referral happen.

Contacting the Bristol Royal Hospital for Children Disability Team



If you are reading this and your child, or one you look after, has both CHD and a learning disability, or ASD (autistic spectrum disorder) then let us know via email and we will add the alerts and send you the hospital passport. childrenshospitalpassport@uhbw.nhs.uk



What is a learning disability?

A learning disability affects the way a person learns new things throughout their life.

A learning disability is different for everyone. No two people are the same.

Many people who have a learning disability can work, have relationships, and live alone. Other people might need more support throughout their life.

A person with a learning disability might have some difficulty:

- Understanding complicated information
- Learning some skills
- Looking after themselves or living alone

There is much support available.



Adult Learning Disability and Autism Liaison Service

By Molly Waters, Learning Disability and Autism Liaison Nurse,
University Hospitals Bristol and Weston

Our work with adult patients with congenital heart disease

We work closely with the Bristol Heart Institute (BHI) to ensure patients with learning disabilities are supported and their needs are being met, focusing on reasonable adjustments under the Equality Act (2010).

There are **person specific adjustments** that help a person with learning disabilities to access health services in the same way a non-disabled person would.

Who are we and what do we do?

University Hospitals Bristol and Weston set up the learning disability liaison team to ensure patients have equal access to health care to reduce health inequalities.

As a team we support all patients over the age of 16 with a formal diagnosis of either leaning disability and/or autism. Studies have shown that 10% of Adult CHD patients have a learning disability (NHS England, 2016). Each hospital will now have a learning disability team. Please contact your local team for information and support.



Support during an admission – Reasonable Adjustments

We should receive referrals for all patients who have learning disabilities/autism. We would complete our initial assessment which helps to identify reasonable adjustments for the patient. These could include:

- ⦿ **Mental capacity assessments** and best interest meetings for patients needing cardiac surgery.
- ⦿ **Longer appointment times**
- ⦿ **Support to facilitate access** to the outpatient department and planning for surgery
- ⦿ **Adapted information** – we can turn hospital leaflets into easy read formats to help support understanding with pictures and simple sentences. We have a collection of easy read information – please contact us for specific resources.

- ⦿ **Side room** – if the patient struggles communicating in the ward bay environment or has sensory issues, a side room will help them to be able to access the care in a better way.
- ⦿ **Improved sensory environment** – we have access to sensory items/toys as well as games and art equipment to offer to patients who may not be comfortable in the hospital environment. We can also adapt rooms for the patient to make things feel less clinical if this would reduce anxieties.
- ⦿ **Open visiting hours/overnight stays** – if a patient is anxious or cannot communicate all their needs, families/carers can stay with the patient to help support on the ward.

These are just some of the more common options – all adjustments are person specific. Please aim to implement reasonable adjustments in your area of work to support our patients!

If a patient with a learning disability or autism is being seen at the Bristol Heart Institute – please refer to us!

Contact details for the Bristol Heart Institute Learning Disability and Autism Team



Phone: 0117 342 1707



Email: learningdisabilities@uhbw.nhs.uk autismliaisonservice@uhbw.nhs.uk



Staff Photographic Competition #4: 'Changing Seasons across the Network'

Throughout September/October 2023 we received many 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.swschd.co.uk/en/page/photographic-competition>

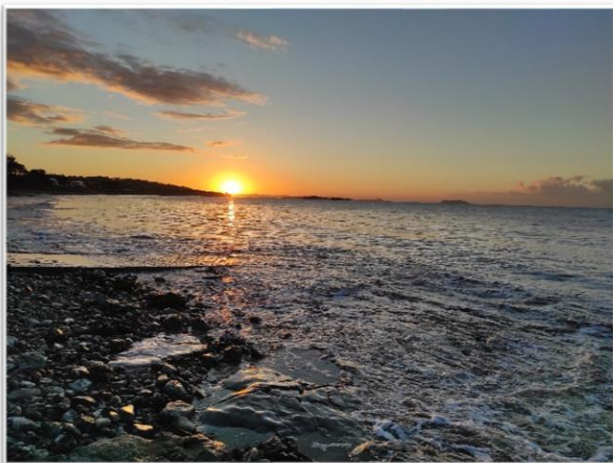
The theme of nature and wellbeing has never been so relevant; getting out into nature can have a huge positive impact on our mental health as well as physical health.

Winner

We are delighted to announce that Amanda Doyle, Cardiology Medical Secretary, in Cardiff, Wales, is the winner capturing the early morning dew at Heath Park.



Runners Up



'Sully Island at Sunrise'
Dr Dirk Wilson
Consultant Cardiologist, South Wales



'Avebury Sunrise – work commute'
Jane Barkshire
Assistant General Manager, Swindon

The staff competition will open again ahead of the spring 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: Bethan's story

Hi, my name is Bethan. I am 15 years old, and this is my patient story.

My diagnosis

I was born in Withybush General Hospital (West Wales) in 2007 and diagnosed postnatally an hour after birth. I have complex transposition of the great arteries (TGA), nine ventricular septal defects (VSD's), and pulmonary stenosis. I had an atrial septostomy in 2007, a Mustard procedure, dominant VSD closure in 2009, and exercise intolerance (desaturation and breathlessness).

Atrial arrhythmia was found in 2023, when visiting Bristol for my cardiac catheter pre-admission appointment. I didn't go home that day and had my Electrophysiological Study (EPS) and ablation three days later. It was a scary experience.

My memories from childhood.

I don't remember being an inpatient as I was too young but, as an outpatient I enjoyed getting stickers and certificates (I still have a collection). It helped seeing doctors and nurses I knew at appointments.

At home and school, I was always treated differently. At home I got jealous of my brother, he could do things that I wasn't allowed to, like going on the trampoline. I got out of breath quickly, so couldn't play for long.

Hospital

Since my last admission to Bristol, when my arrhythmia was picked up, I have been terrified of hospital trips. It's the uncertainty of what will be found or what might happen. On the ward I was well looked after and am very grateful for the surgeon who talked to me about my heart. Even though I fear hospitals, I would tell others not to worry, they will be well looked after, it is a safe place to be.

Everything is far from where I live. Bristol is a 3-hour drive but with regular stops due to my Mum's health; it can take up to 5 hours.

Social experiences

My experience socially is very difficult. At school, I was treated differently and removed from some classes, such as drama and physical education, without adaptations made. I sat in the rain watching my peers run around. It made me feel sad, put out and not good enough. I was bullied because I was the odd one out despite lots of input from my doctor and nurses who tried to help.

I struggle every day with simple things, like getting dressed or climbing stairs. I feel I can't do anything sometimes which isn't a nice way to feel.

Transition

I recently met my new transition nurse. I feel like I know my paediatric team well and I am nervous meeting the new adult team. My first transfer appointment will be in Carmarthen, 45 minutes' drive away and future appointments in my local hospital, Withybush. It would be nice if my transfer appointment could be here also. I don't think I'll ever feel prepared until I actually transfer.

Feeling empowered

From a young age my cardiac team always talked to me, as well as my parents. The surgeon in Bristol drew a diagram and explained everything and didn't leave my room until I understood. It meant a lot. Being able to meet the team before my ablation put me at ease. As an inpatient in Bristol, communication about my care and what was happening was always good. My parents and I can always contact someone from my team to ask questions.

Challenges

I struggle physically and mentally. Money and travel were challenging. We struggled financially with trips and stays in hospital. Sometimes accommodation wasn't available, so my parents needed to pay for hotels. There was limited expertise in my local hospital which meant travelling to Carmarthen.

Raising awareness

I would like people to understand that children and young people with a heart condition can struggle with lots, like bullying, feeling different to their friends, physical activity and anxiety. I would really like to get to know other people in my area with heart conditions like me, and maybe get help from my cardiac team to facilitate this – like support groups.

We've been very happy as a family with our overall care.

Bethan shared her experience of cardiac care at the CHD Network Board in October 2023 – this meeting is attended by staff and patient representatives from across the South Wales and the South West region.

Bethan's story was also shared with consent at the National CHD Networks Annual Conference in November 2023, attended by CHD stakeholders across the country and beyond.



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

Scan this code with your phone to visit the Network website



Thank you for reading!

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

spring 2024, please contact

Rachel.Burrows2@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 Rachel.Burrows2@uhbw.nhs.uk requesting our newsletter