



Newsletter



Updates from
your CHD Network

Inside this edition

- Clinical Director's Introduction...2
- Cardiac transition...3
- New clinical updates...4
- Education and training...6
- Congenital echocardiography training...7
- Welcome and staff changes...8
- Gloucestershire ACHD nurse...9
- Parent and patient voice...10
- South Wales patient engagement...11
- Network updates...12
- Staff photo competition...13
- Rebecca's patient story...14
- Somerville Heart Foundation...15
- Useful contacts...16



Introduction from our Clinical Director Dr Stephanie Curtis

Welcome to the Summer 2024 edition of the South Wales and South West Congenital Heart Disease Network newsletter!

As we move into better weather, we are sad to have to announce a formal farewell to some of our colleagues. Our Lead Nurse Jess has left to train to become an Advanced Clinical Practitioner. Whilst we wish her all the best in her career development, we will miss her positivity and endless enthusiasm. We also lose Dr Eva Kapravelou, Consultant Paediatric Cardiologist (enviously!) to British Columbia.

To soften the blow, we welcome new staff to the region and, having participated in the ACHD outreach clinic in Gloucester over many years, I am delighted that there is now an official ACHD nurse, David Withers, in post. David has already made a huge difference to the running of the clinic and patient support. Dr Khan and Dr Edwards join and re-join the Welsh team and Dr Mari Velasco Forte will return to the Bristol Royal Hospital for Children as a Consultant and we welcome them warmly to the Network.

This newsletter brings the usual mix of articles, which I hope you will enjoy. Rebecca's story on page 14 and 15 is moving and poignant and goes to the heart of one of the visions of the Network: seamless care of patients from early childhood right through adolescence and adulthood and across the region. It illustrates how having a family is not always straightforward and the importance of psychology support for our patients. We wish Rebecca all the best for her upcoming surgery.

We welcome a new Chair for our Network Board, Dr Radwa Bedair. Radwa has led the development of the new sinus venosus atrial septal defect stenting in Bristol, which you can read about on page 4 and 5. We are both proud and impressed in equal measure to see how well this new procedure is developing and how much of a difference it had made to patients lives. Now most of them can undergo a catheter-based procedure rather than open heart surgery, which is something that we had not previously thought possible for this condition.

When I first came to Bristol in 2003 none of the adult trained echocardiographers were able to scan congenital heart disease patients. Now, not only are all of the echocardiographers fully trained, but are proficient in even the most complex patients. This is progress indeed! The excellent new ACHD webinars have been extremely well received and I would urge you to attend if you can.

Over the summer we will be turning our attention as a Network team to the self-assessment virtual visits for the Southwest level 3 centres. We have had excellent engagement with the centres so far. Adherence to the NHS England CHD standards is high and we hope to be able to support Trusts in improving services further.

I hope you all have a wonderful summer and stay well!

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](#)

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

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

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

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



Meet Karina, Paediatric Cardiac Transition Nurse Specialist

My name is Karina Howell, and I am a Paediatric Cardiac Transition Nurse Specialist. I am based in the University Hospital of Wales in Cardiff, but I look after patients from age 12 years to their transition to adult services across South Wales.

What is the cardiac transition service?

Our cardiac transition service is a programme designed to support young people with heart conditions to gradually move from the children's services to adult services. The service educates patients on the heart condition that they have and any medications treatment or surgeries that maybe required. It aims to give young people the confidence to manage their condition and give them the opportunity to know the adult team they will eventually transfer to.

What age do patients tend to transition between children's and adult CHD services in South Wales?

Our transition service starts for patients at 12 years until the age a patient transfers to adult services (usually between 16 and 18 years of age).

Designated teenage clinics

Patients at the age of 12 start to attend a designated teenage clinic with myself and a Cardiology Consultant. Currently these clinics are held in University Hospitals Wales (UHW) in Cardiff, but we are starting to roll them out across South Wales. These clinics are a good place to discuss lifestyle, health and the many different aspects of teenage life whilst living with a heart condition.

Transition clinics

At 16 years of age, a patient will be referred to one of our transition clinics. We hold transition clinics in each Health Board across South Wales. The clinics are a collaboration between myself, the Adult Congenital Heart Disease Clinical Nurse Specialist team from UHW, a Consultant Cardiologist, one of the Adult Consultant Cardiologists and Xander Patel-Cook, Congenital Heart Disease Youth Worker from Youth At Heart.

These clinics are a great way of getting to know the adult team and to see the adult and paediatric team working collaboratively for a smooth and thorough transfer of care. Every patient that attends a transition clinic will also receive a comprehensive health care plan full of information related to their heart condition.

The transition service is rapidly evolving, and we are always trying to improve and expand our service to meet the needs of our patients and families.



Xander at Youth at Heart

The journey from child to adult care is known as 'transition.' Whereas 'transfer' is the actual move date.



The experience of transition is different for every young person, and there is much support available.

When you make the transition to adult care and move from a paediatric specialist to an adult hospital or clinic, you'll naturally take more responsibility for managing your condition.

This may feel a bit daunting at first, and it's normal to have some questions along the way.



Find out more about ways to manage your heart condition as you grow up, on the British Heart Foundation website: www.bhf.org.uk

- [The journey from child to adult care - BHF](#)
- [12 questions you should read before seeing your doctor - BHF](#)
- [Medicines for heart conditions - Treatments - BHF](#)





What's new: clinical updates

Covered Stent Correction for Superior Sinus Venosus Defect Introducing a new procedure at University Hospitals Bristol & Weston

By Dr Radwa Bedair, CHD Network Board Chair and ACHD Consultant Cardiologist



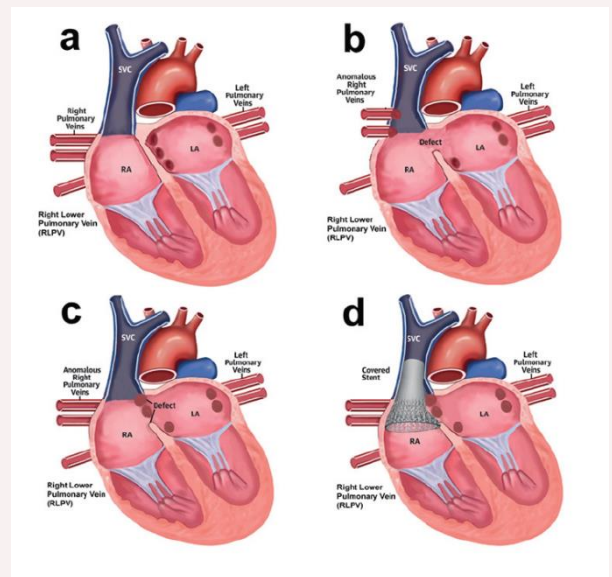
A little background from our patient information leaflet

Atrial septal defect (ASD)

The heart has four chambers. Two receiving chambers called atria and two pumping chambers called ventricles. The wall that separates the right and left atrium is called the atrial septum. A hole in the atrial septum is called an atrial septal defect (ASD).

What is Sinus Venosus Atrial Septal Defect (SVASD)?

There are different types of atrial septal defect, depending on the location of the hole in the atrial septum. Sinus venosus ASD is a less common type of ASD, where the hole is high in the atrial wall. Commonly this defect is also associated with abnormal connection of the pulmonary veins (blood vessels returning blood from the lung to the left atrium). This is shown in the diagram here.



Hansen, J.H. et al. J Am Coll Cardiol. 2020;75(11): 1266-78

What symptoms does this cause?

SVASD leads to an extra shunting of blood to the right side of the circulation which causes enlargement of the right-sided structures (right atrium, right ventricle and pulmonary artery).

Patients can remain without symptoms for years but most eventually develop symptoms, including heart rhythm disturbances, breathlessness on effort and exercise limitation. Even in the absence of symptoms, if there is enlargement of the right side of the heart there is an indication to treat this condition to prevent progression to heart failure.



Image of a stent, courtesy of Numed Medical

How can SVASD be treated?

Surgical repair, through open heart surgery and the use of a heart-lung machine, used to be the only way that this condition could be treated.

A new treatment option

In 2014, a novel approach to treating this condition through transcatheter, minimally invasive procedures was first described. This involved placing a large covered stent (an expandable metal scaffold with covering around it) into the junction between the superior vena cava and the right atrium, leading to separation between the superior vena cava in front and the pulmonary veins behind, with the pulmonary veins being redirected towards the left atrium.



Continued...

Following the initial case reports, this procedure was adopted in the United Kingdom and worldwide with 380 patients receiving this treatment worldwide, 77 of whom had the procedure in the UK. The published data now shows that this procedure is effective in treating the condition, by re-establishing a pathway between the pulmonary veins and the left atrium and sealing the atrial septal defect. Short term results at one year follow-up show a significant improvement in the size of the right heart, with some patients' right ventricles returning to a normal size.

Since 2020, we have worked closely with the team at Guy's and St Thomas's Hospital (London), who have the largest experience of this procedure in Europe, to assess suitability for the procedure, evolve the procedural techniques and learn to perform this procedure.



Governance and regulation approval

The procedure was approved by the University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) New Procedures Committee in November 2022, following the Medical and Healthcare Products Regulatory Agency (MHRA) approving UHBW as one of the sites in the UK that can perform this procedure using the 10 Zig stent in August 2022.

The MHRA approval is subject to regular reviews and extensions of the approval if the outcomes and data are satisfactory. Our outcomes and data are audited annually in the Trust, reported to the National Congenital Heart Disease Audit (NCHDA) as for all congenital catheter interventions, and also submitted to the worldwide database for this procedure.

To date, 12 patients from our South Wales and South West CHD Network have had this procedure performed, with excellent results so far.

The team are hugely excited that we are able to offer this keyhole procedure to our patients and avoid the need for open heart surgery for the right patient, sending most patients home the following day. All our patients are discussed at the multidisciplinary team meeting to agree an indication for treatment and consider the options of transcatheter versus surgical treatment. Our surgical colleagues have been fully supportive.



Award nomination: Our team was nominated for a recognising success award for innovation and are fully committed to continuing to develop this procedure, offering this to all suitable patients and diligently monitoring our outcomes. *Congratulations to you all!*



How to access the patient information leaflet



Use the QR code or link below



https://uhbw.mystaffapp.org/diliboards/223/diliboard_content/s/13420/document_view.pdf





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).

2024 New ACHD Echo Webinar Series: A Gateway to Congenital Heart Disease Education

By Gui Rego, Lead ACHD Echocardiographer at the Bristol Heart Institute

Embark on a monthly journey of knowledge and expertise with the new South Wales and South West ACHD Echo Webinar series. This is designed to empower professionals in adult congenital heart disease (ACHD) echo across South Wales and South West England regions.

Tailored for individuals pursuing ACHD accreditation or seeking in-depth knowledge of congenital heart disease, the webinars serve as a comprehensive resource aligned with the accreditation process syllabus.

Organised by Bristol Heart Institute's lead echocardiographer, Sarah Fairbairn, and lead ACHD echocardiographer, Gui Rego (both pictured below), in collaboration with Dr Stephanie Curtis, ACHD Consultant Cardiologist, these sessions also aim to offer British Society of Echocardiography certification points.

Since its launch in January 2024, the series has gathered praise, with the fourth session on 23rd April marking another milestone. Exceptional participant feedback reflects the growing demand for such educational initiatives, extending the series' reach to regions such as London, the north of the UK, and other countries like Portugal.

With sessions currently scheduled until July 2024 and a commitment to ongoing development, the series promises a continuum of enlightening content. While future plans are on the horizon, organisers emphasise a commitment to refining and expanding the webinar based on valuable participant feedback.

Well done to Gui and Sarah, and all the webinar speakers, for driving the success of the South Wales and South West ACHD Echo Webinar series.

Join us in unravelling the complexities of congenital heart disease through engaging and informative webinars. Stay tuned for future sessions!



What's coming up regionally?

- ❑ CHD Network psychology study day, 19th June 2024
- ❑ Welsh Paediatric Cardiovascular Network & CHD Network Spring Meeting, 14th June 2024. Theme: morphology, ECHO and rhythm.
- ❑ Transition study event, 27th June 2024
- ❑ ACHD study day (aimed at nurses, AHPs and junior doctors), 1st October 2024. Theme: Fallot's tetralogy



SWSW CHD Network NHS Future Platform

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

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

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



Congenital Echocardiography Training in the Network

By Owen Burgess, Deputy Head Cardiac Physiologist, Bristol Royal Hospital for Children

NHS England CHD Standards state: "all local children's cardiology centres must have a cardiac physiologist with training in congenital echocardiography".



Our congenital echo training programme has been working with the South-West's Level 3 centres since November 2021. The team are very grateful for the continued financial support from NHS England, which allows us to deliver this.

There has been strong progress towards the project's aims of achieving a physiologist with congenital echo accreditation and establishing physiologist congenital echo clinics in each Level 3 centre across the Southwest.

The programme has worked closely with Barnstaple, Taunton, Torbay and Plymouth.
Within these services there are some noteworthy achievements to report:

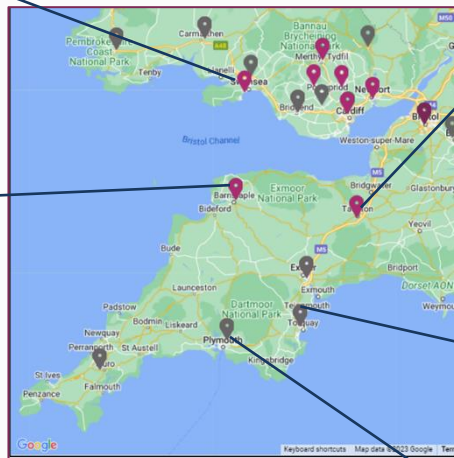


Noteworthy achievement (not directly related to the project) must be recognised. Congratulations to **Marian Thomas** from **Swansea**, for passing the European Association of Cardiovascular Imaging Congenital Echo Exam in December 2023.

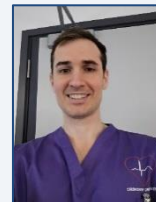


Amy Szewiel and **Nelisa Sagrado** (**Taunton**) have both studied very hard and sat the British Society of Echocardiography Congenital theory exam on March 6th, they nervously await their results!

In **Barnstaple** (as the physiology service did not have capacity for a physiologist to complete the full accreditation process) we have undertaken a local competency assessment (consisting of practical assessments and sitting our Mock BSEcho exam) with **Sally-Anne Pester** and **Dr Andrew Arend**.



Congratulations to **Sinu Thomas** (**Torbay**) and **Rubens Santana-Neto** (**Plymouth**) who have both successfully passed the British Society of Echocardiography Congenital theory exam and are close to completing the practical aspects of the accreditation process.



There are plans afoot to begin training with Physiologists from Great Western Hospital Swindon from April too.

The team are very grateful for all the hard work and support for the project across the Network. There are too many people involved to mention individually, but the collaboration of cardiac physiology teams, consultant paediatricians with expertise in cardiology (PECs), cardiologists and admin teams has been crucial to the success experienced so far. **Congratulations to those involved!**



Welcome



Update on team changes

Welcome to the Network Dr Elinor Edwards, Cardiology Registrar at Cardiff ACHD team, and also to Dr Aisal Khan, ACHD Fellow in Cardiff. Welcome to Dr Jane Bromilow, Consultant Paediatric Cardiologist in Cardiff.

We also welcome Lydia Spittal, Paediatric Clinical Nurse Specialist in Bristol. We congratulated Dr Mari Velasco Forte appointed as substantive Consultant in Paediatric Cardiology with subspecialty expertise in cardiac imaging at the Bristol Royal Hospital for Children.

We bid farewell to Dr Eva Kapravelou, Consultant Cardiologist at the Bristol Royal Hospital for Children, who left the team in April 2024.

We also said goodbye to Laura McCarthy, Transition Clinical Nurse Specialist in Cardiff, who also left in April.

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

Introducing our new Board Chair, Dr Radwa Bedair



Dr Bedair is a consultant cardiologist in adult congenital heart disease (ACHD) at the Bristol Heart Institute. She trained in London and moved to Bristol in 2014 to begin her consultant career.



Clinical interests & management experience

Dr Bedair's clinical interests include congenital catheter interventions, pulmonary hypertension and the Fontan circulation. She leads the training programme for ACHD in South-West England and regularly teaches at national and international meetings.

She has experience in management having served as Clinical Lead for the Adult Congenital Heart Disease service as well as the Clinical Lead for Audit and Clinical Governance for the Bristol Heart Institute.



Vision for the Network

Dr Bedair has been supporting the Network since its inception and commenced in her role as our new Network Board Chair in April 2024. She is keen to welcome colleagues, patients and carers from across the Network regions, to share their views and experiences through the Board meetings.



Her vision is for an inclusive Network that can collaborate with other congenital, cardiac and non-cardiac Networks to help shape the future direction of congenital heart disease care at a time of potential change and challenges for the NHS.



Outside of work

Dr Bedair enjoys running and growing vegetables at home.

What is the Network Board?

The CHD Network Board meets every quarter, with around 30-40 representatives in attendance from across South Wales and the South West of England. This includes doctors, nurses, allied health professionals, commissioners, managers, and patient representatives.

The Board is responsible for ensuring the Network delivers its aims and agreed activities.



Reflections from our Lead Nurse, Jess Hughes, on her time in the CHD Network

“Working in the South Wales and South West CHD Network has been a fantastic experience and highlight in my career pathway so far. The values of the Network that centre around equity of access for all are closely aligned to my own personal values and something I feel passionate about.

Working in the field of congenital heart disease for the past 15 years, I have witnessed firsthand the struggles and challenges that families and patients face when dealing with this complex disease. Helping to improve this experience is something I have been very proud to be a part of.

I believe that to make positive change, patience, engagement and listening to patients’ views are key. Alongside this, teams that are willing to say ‘yes’ even in the face of challenging working conditions. The hurdles faced along the way only add to the experience and help to inform the choices made on the next project. I have been so lucky to work with teams in each centre who strive continuously to improve their services. They are ‘yes’ people and this has made my job so much easier.

I hope that the positive contributions to the Network I have made continue to make a lasting impact through the brilliant team carrying on this work and most of all, the people on the ground who make it all happen.”

Meet David

Adult CHD Nurse in Gloucestershire



Gloucestershire Hospitals NHS Trust has run ACHD clinics for many years. Local Consultant Cardiologist Dr David Lindsay from Gloucester runs these clinics alongside a visiting ACHD Consultant Cardiologist from the Bristol Heart Institute, and these occur every other month.

The role of the ACHD Nurse within the Gloucestershire Trust started in September 2023, with funding for one day a week. David Withers (pictured right) has been supporting ACHD patients in this ACHD nurse role since then. On joint clinic days, David sees young patients attending these clinics, discusses transition to adult services and supplies young person information packs.



Additionally, for these clinics, all patients are contacted upfront in an attempt to address any attendance issues. The clinic consultants are also given a researched patient summary list to highlight each patients’ key issues. David has set up an ACHD Telephone Advice Line and is there to respond to any calls from local ACHD patients.

David has been creating an awareness of the online “Patient Support Sessions” (provided by Pauline, BHI Clinical Psychologist) and the “Let’s Talk” sessions (presented by Youth at Heart), by direct contact with local patients and by arranging with the Gloucestershire Trust to advertise these events on their Facebook page. He is currently exploring ways to address the joint clinic waiting lists so that patients can be seen in clinic sooner. Watch this space!



Patient and parent voice in the Network

By Sheena Vernon, Network Lead Nurse

We have had a small group of excellent patient and parent representatives since the Network began in 2016. This year we have had the opportunity to develop the group further.

In March 2024, we held a meeting with our existing patient and parent representatives and several new patients who had expressed an interest in becoming more involved to members of their clinical teams.

We outlined the world of congenital heart disease, the role of the Network and its national context, and the type of patient and parent involvement opportunities. Current patient and parent representatives shared their background and examples of work they have been involved in.

Those interested in becoming more involved shared their background and the skills they felt they would bring to this role. They had a range of experience and skills which would contribute significantly to the Network activity.

After the meeting five people were keen to become more involved and each had an online interview. We have a job description and written contact for the role.

Current areas of involvement include:

- Attending the Network Board meetings, including a pre-and post-meeting briefing.
- Participating in small task and finish groups.
- Commenting on patient information, the website, leaflets and pathways.
- Contributing their lived experience in patient stories, newsletter articles.
- Representing the wider patient population is an important part of the role.



We are very proud to have such an engaged group of patients and parents in our Network and are so grateful for their time and invaluable input.



Read all about it!

South Wales ACHD Service Book Club

By Frankie Carlin, CHD Network Patient
Representative

Healing Hearts and Minds by Tracy Livecchi and Liza Morton is the book that we all, as patients, wish had been written years ago. It validates all that we have been and continue to go through.

It is so important that, when discussing it with the cardiac nurses and our wonderful psychologist, Anna McCulloch, we decided to trial a book club to talk about it. After many conversations it was decided that via a virtual platform would work best as we are all in the safety of our own homes and no one had to travel.

We take two chapters a month and use the information as a springboard to start a conversation. There is absolutely no pressure to talk or take part in the meetings or even to have read the chapters – just being there is enough.

We have found that the sessions allow us to have open and honest conversations about the topics read and we are gently guided and supported by Anna throughout.

It is invaluable to be able to listen to other people's thoughts, experiences and words of wisdom. We have been able to reflect on our own experiences and how they have shaped us, and we laugh and cry at all the highs and lows that we, as heart patients, have been through. We realise that we are not alone.

If you are interested in joining the South Wales ACHD Service book club please contact:

Cardiac.psychology.cav@wales.nhs.uk



South Wales ACHD Patient Information & Engagement Day January 2024

By Sarah Finch, ACHD Clinical Nurse Specialist

The South Wales ACHD Patient Information & Engagement Day, went ahead on the 27th January, at the Waterton Centre, Bridgend. The venue was chosen largely for its location - close to the M4 transport links and also a central point across the South Wales region.

The day was a huge success with around 80 participants; including patients, families, carers, professionals and charity partners. Photo to the right is of event organisers, Anna McCulloch, Sarah Finch, Bethan Shiers and Kindre Morgan based in Cardiff.



The programme

The Information day included presentations on topics such as lifestyle, exercise in ACHD, catheter lab interventions, psychology, pregnancy and benefits advice. Our patient representatives (pictured below) were incredibly brave and provided an insight on their experiences of our 'ACHD patient well-being group' and the positive benefit of peer support. We were also able to hold some interactive well-being sessions and St Johns Ambulance undertook resuscitation demonstrations and CPR training.

We ended the day with the opportunity for attendee's to 'Ask the Expert Panel' – this provided great interaction and discussion.

Event feedback

Throughout the day we sought feedback from those in attendance. Feedback was very positive and those who attended the day valued the experience and requested the opportunity to attend and / or participate in future educational or well-being events.

"Excellent variety of presentations and sessions which covered all areas. Really informative for both patients and health professionals"

"Hearing from the patients reps and meeting other people with a heart condition was really helpful"

"An opportunity to meet other patients and their families and to realise and appreciate that everyone with CHD has similar challenges regardless of their individual condition"

"Wonderful event. I feel grateful to have attended and I feel so many more would love things like these"



What's next?

As a Team and following evaluation of feedback we are reviewing options to engage with patients and provide pertinent information on a variety of platforms.

We plan to repeat this event next year based on a similar model. We are very grateful to the cardiothoracic directorate for their financial support – enabling this day to take place.



Network update

By Michelle Jarvis, CHD Network Manager

Introduction

Thank you to all those I have met so far for such a kind welcome into post, and I very much look forward to meeting more of you over the next few months. I've been really impressed to hear and learn about such amazing and often innovative work being progressed by Network members in developing and improving pathways and services for patients, families and staff - all this despite the operational challenges and pressures that come with Winter! We look forward to sharing more detail with you on the successes and challenges of 23/24, in a few months' time, through the Network annual report.

I've been lucky to attend some excellent teaching and engagement events as part of my induction as well as meeting the fantastic group of patient representatives. You can find out more about Network events on our website (www.swswchd.co.uk) and also consider a visit the Network FutureNHS platform which holds lots of training, education and learning resources for healthcare professionals (<https://future.nhs.uk/system/login>)

Looking Ahead

You can see the Network plan on a page document, shared at the Network Board meeting in January 2024, on our website. This plan details the areas of priority and focus for the coming year for the Network. Now this is agreed, we look forward to working together on delivery of some really exciting workstreams involving stakeholder representatives across the Network. Please do get in touch if you would like to get involved or discuss further (michelle.jarvis@uhbw.nhs.uk).

Self-Assessment audit process in South West

The core Network team are all really excited about our virtual 'visits' to the South West England centres when the self-assessment process start in May 2024. The self-assessment process involves measurement of the services within each of the centres against the relevant NHS England CHD service specification standards. The standards describe the way in which CHD services are to be organised and run. They help to ensure that all patients have access to high quality care and aim to minimise differences between different hospitals.

As many of you will recall, the self-assessment process was completed for the South Wales centres last year and highlighted improved compliance against the standards from the previous review in many areas. As part of the process, action plan recommendations were developed to support further improvements to CHD services within South Wales.

Through the planned South West England self-assessment process, we are really looking forward to; understanding how each of the services are getting on, working together to identify any areas for improvement and looking at where the Network can best support in improving things to ensure high quality consistent care for patients.



Did you know...

My Staff App is the new digital management platform at University Hospital Bristol and Weston – replacing the Document Management System (DMS).

Our staff from hospitals across the region can register in advance to get access to policies, leaflets and documents.

mystaffsupport@uhbw.nhs.uk

Network dates for your diary!

Key Network meetings:

7th August 2024: Network Board

26th November 2024: Network Board & Clinical Governance

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



Staff Photographic Competition #5: 'In Bloom across the Network'

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

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

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

Runner Up

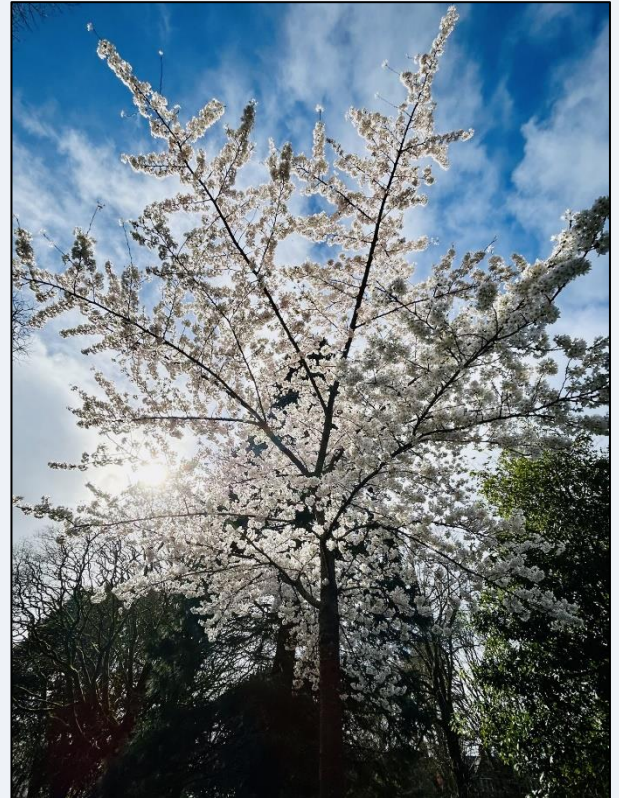
'Freezing Hill Lane on my way to work at the Royal United Hospital on a cold Saturday 2nd March 2024'

Dr Muhammad Addin,
Consultant Paediatrician with
Expertise in Cardiology, Bath



Winner

We are pleased to announce that Sarah Finch, ACHD Clinical Nurse Specialist in South Wales, is the winner capturing this lovely cherry blossom tree in full bloom in Roath Park, Cardiff.





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

By Rebecca, patient representative

My name is Rebecca and when I was 6 years old, it was discovered that I had a congenital heart condition. I never had any symptoms of a heart condition, and it was discovered upon visiting the GP when my sister and I had a cough and cold. The GP heard a heart murmur and within weeks I was sent for further investigation which resulted in an aortic aneurysm being found.

A few weeks later I underwent open heart surgery to replace my aortic valve and repair the aneurysm. The surgery was a success and between then and now I have been fortunate to have not needed further intervention. I have taken warfarin since the surgery and whilst this has had its ups and downs, generally, it hasn't been overly problematic.

I have had excellent care from staff members in the cardiology department at University Hospital Wales (UHW) and in 2012 this was put to the test when I wanted to explore the option of pregnancy. I was advised that I would need an exercise stress test and based on the results was told that it would be possible but not without its risks.

In April 2012, we sadly experienced a miscarriage, and this was managed by the maternity staff at UHW because I was taking anticoagulants. In April 2013, we fell pregnant again and I immediately stopped taking warfarin and began injecting Clexane daily. I suffered with morning sickness and tiredness as was to be expected but at 12 weeks pregnant my echocardiogram images suggested that one of my valve leaflets wasn't opening.

I was admitted to the Coronary Care Unit from my outpatient's appointment and sent for a CT Scan to further investigate. Thankfully, the CT Scan images showed the valve working as it should be, but a TOE was recommended just to make sure all bases had been covered. Having a TOE whilst experiencing morning sickness was not a medical highlight of mine! My warfarin was recommenced, and I was discharged once my INR was back in range.

Glossary: What is a TOE?

A transoesophageal echocardiography, or TOE, takes detailed pictures of your heart from your oesophagus (the tube that connects your throat to your stomach) which lies behind your heart.

This test is used to get closer and more defined images of the heart as it can detect areas of the heart that are not as easy to see with a standard echo.

Find out more on the British Heart Foundation website
www.bhf.org.uk



At my 20-week scan an anomaly was detected on baby's kidneys and I was referred to the paediatric nephrology department to ensure when baby was born, antibiotics would be arranged until a kidney scan had been undertaken.

As the third trimester approached, discussions started to take place about how our baby would be delivered. I had appointments with obstetrics, cardiology and anaesthetists to try and make a decision on the best method of delivery. It was eventually decided that I should not risk labour and that the baby should be delivered at 37 weeks' gestation via caesarean and under general anaesthetic. I just remember being willing to follow the advice of my medical team and doing as I was told!



Rebecca's story continued...



On 10th December 2013 our daughter, Emily, was delivered with no complications. A kidney scan revealed cysts on her kidneys but to date these have caused no issues.

Emily is now 10 years old and is healthy and active. She will be having an echocardiogram this year as I have recently had genetic testing which has discovered that I have Polycystic Kidney Disease (PKD2) and there is a small possibility that this could be linked to my cardiac condition. It is likely that Emily also has this condition, but this has not been officially diagnosed.

Since Emily's birth, I have started to suffer with mental health issues from living with a congenital heart condition. In 2014, I was due to have open heart surgery to replace my aortic valve and repair another aneurysm. This surgery was cancelled quite last minute as it was felt it needed paediatric surgical input and that it should be carried out in the Bristol Heart Institute.

I am still yet to have this surgery and the uncertainty around this has caused me a great deal of stress and anxiety. I started to suffer from panic attacks when I went out alone and it had a negative impact on my day-to-day life.

In 2022, I was contacted by Dr Anna McCulloch (Consultant Clinical Psychologist) and invited to take part in the Down to Earth programme. This has been such an invaluable experience and has enabled me to meet others living with congenital heart conditions who have had surgeries and interventions and understand the thoughts and feelings this can bring.



We have developed very close friendships as a result of this group, and I am in regular contact with the participants – my 'Heart Friends'. These groups also resulted in a closer relationship with the cardiac team and specialist nurses which has been highly beneficial when needing to speak to somebody about an issue or chasing up appointments or results.

You can find out more about the Down to Earth wellbeing group for patients with CHD in the Spring 2023 newsletter

<https://www.swswhd.co.uk/en/wall>

I am now on the waiting list to have the surgery carried out at the Bristol Heart Institute. I think the surgery will be quite complex and it brings with it a whole host of thoughts and feelings.

Rebecca has recently joined our Network patient representative team and shared her experience of cardiac care at the CHD Network Board in April 2024 (see page 8)



On Saturday 11th May 2024, the Somerville Heart Foundation (www.sfhearts.org.uk), a patient organisation for young people and adults with a heart condition, held their annual national conference in Bristol.

This event for patients and families as well as healthcare professionals was in collaboration with the Bristol Heart Institute and the CHD Network.

The programme included talks from some of the Bristol Heart Institute team and patients speaking from lived experience, plus table discussions and a Q&A session. In the afternoon, delegates could attend one of three workshops on finance, menopause or a virtual reality view of different congenital heart conditions.

Photo below of our Lead Nurse Sheena Vernon and ACHD Clinical Nurse Specialist Rachel Wyatt, giving their presentation.





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 winter 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