

Newsletter

Updates from
your CHD Network

Inside this edition

Clinical Director's introduction...2

What is a JCC or MDT?...3

Cornwall's cardiac service...4

South Wales ACHD wellbeing group...6

Physical activity and exercise...7

Welcome and staff changes...8

New BHI ACHD consultant...9

Education and training...10

New Research Lead...11

Network update...12

Taunton's national award...13

Cardiac physiology ...14

Book reviews ...15

Staff photo competition ...16

Summer travel advice...17

Kal's ACHD patient story...18

Useful contacts...20





Introduction from our Clinical Director Dr Stephanie Curtis

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

As always, we have a lot to talk about with so much fantastic work being done across the whole region.

We have had a difficult winter with unusual amounts of infections filling our intensive care beds and affecting our surgical programme, but recovery is underway and we continue to climb the hill of service restoration after COVID-19. Spring is most definitely in the air!

This season, we are delighted to welcome so many new members of staff to our CHD family in the region. In particular, I am always pleased to see Trusts supporting the role of the Link Nurse, as it makes such an enormous difference to patient care on both a practical and pastoral level.

The Bristol Royal Hospital for Children has been recruiting new consultants to replace those who left to work abroad or are retiring. This will bring welcome stability for patients and families in the region. Also on the new faces front, I am delighted that we have also recruited Professor Giovanni Biglino to be our Research Lead. Having worked with Giovanni on several projects, I know that he will bring enthusiasm and passion to this role and his links with CHD research throughout the country will no doubt drive things forward nationally too.

I am regularly overwhelmed by the dedication of staff in the NHS across all disciplines and the recent strikes have shown just how much everyone pulls together in times of crisis to support each other in order to continue to care for patients and their families.

There are so many things to comment on in this Spring Newsletter that I will leave you to read it and enjoy. A big thank you to Rachel Burrows for producing another high quality newsletter. I hope you enjoy reading it as much as I did!

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.

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What is a JCC or MDT?

By Jess Hughes, Network Lead Nurse

What does JCC stand for?

A Joint Cardiac Conference, is also known as an MDT or multi professional meeting. It is a meeting of different types of specialist health professionals in congenital heart care, including:

- ♥ Cardiac surgeons
- ♥ Anaesthetists
- ♥ Radiologists
- ♥ Cardiologists
- ♥ Specialist nurses
- ♥ Physiologists

As a Network, we have received some patient feedback that the JCC can be a difficult process to understand. We have been working to help patients understand the process better. This article aims to de-mystify the JCC/MDT.

When and where does it happen?

The meetings may be held virtually or face to face and are based in Bristol, hosted by:

Bristol Royal Hospital for Children: Every Monday afternoon and Friday morning

Bristol Heart Institute: Every Monday morning

What is discussed?

Patients' information and tests are collected and presented to the team by their consultant, they will ask for the teams opinion on the best course of action for the patient.

It may be that surgery would be helpful, or it may be that a keyhole procedure such a cardiac catheter could be performed. In some cases, a 'watch and wait' approach may be taken, and the patient would be seen in outpatients and continue care with their usual consultant.

How is the information viewed?

Still and moving images are shown on big screens in a meeting room or via a virtual meeting. An expert in these images will talk them through so that the whole team work together to understand the problems and explore solutions.

How long will it take for my case to be discussed?

Cases are discussed at the next available JCC depending on urgency and which operations are taking place each week. You should hear the outcome of the discussions within 8 weeks. This will likely be via a letter containing all the information about what was discussed and the decisions taken to move forward.

- If the decision is to opt for surgery then you will be sent an appointment to meet with the surgical team to discuss the options available
- If the decision is for a keyhole intervention such as a cardiac catheter you may be referred to an interventional cardiologist unless your own cardiologist also undertakes these procedures
- If the decision is to continue to watch and wait you will see your usual consultant in the outpatient clinic to discuss options, for example, different types of medication
- In some cases particularly you may be referred to a different centre with particular expertise in your condition so that their opinion can be sought.



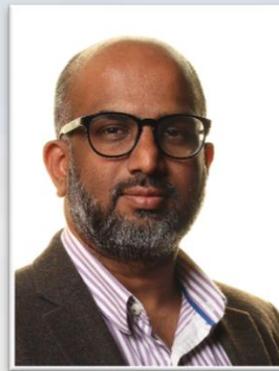
Building a fantastic Paediatric Cardiac Service in Cornwall for the benefit of cardiology patients

By Katy Huxstep & Sam Padmanabhan, Consultant Paediatricians with Expertise in Cardiology

The team in Truro look after one of our largest populations of congenital heart disease patients. The Royal Cornwall Hospital in Truro is one of the busiest district general hospitals in the UK and in a geographically isolated position. The team consists of two Paediatricians with Expertise in Cardiology (PECs), who also work in general paediatrics and on the neonatal unit. There are also visiting consultants from the Bristol Royal Hospital for Children cardiology team who run all day clinics twice a month.

The Paediatricians with Expertise in Cardiology, Dr Sam Padmanabhan and Dr Katy Huxstep (pictured on the right), have been keen to expand their service to provide a better quality of care for the most remote paediatric cardiology patients. This applies to not only patients with congenital heart disease but also those with arrhythmias and inherited cardiac conditions.

After lots of hard work over the last three years, the team are delighted with a number of new additions to the local team and would like to thank the Care Group Management Team for their support with this, and also the vision of the Royal Cornwall Hospital NHS Trust.



Introducing Nina Worrin, Royal Cornwall Hospital's First Paediatric Cardiac Nurse Specialist



Nina is a very experienced paediatric nurse who also has lots of cardiac experience. We are delighted to welcome her to the team two days a week initially. Nina will provide support to the paediatricians and visiting cardiologists from Bristol, but mainly as a point of contact and knowledge for patients and their families and to develop a 'transition to adults' pathway.

We caught up with Nina to find out more...

"I have over 20 years of paediatric nursing experience, and throughout this time I have been fortunate to meet and look after many amazing children with congenital heart disease and their families. I began with 10 years in Bristol Paediatric Intensive Care Unit, which I loved, and gained a huge amount of experience, knowledge and skills to take forward. However, I always knew I wanted to move back to Cornwall to bring up our children and for them to have the childhood that I had living by the sea in a beautiful part of the country.

Since moving back to Cornwall eleven years ago I have worked in our busy local hospital in many different roles and during this time have cared for children with cardiac conditions in varying stages of their journey. This has included children who have needed emergency and high dependency care, inpatient stays, and those who visit regularly in outpatient clinics. All of these experiences have given me a broad outlook and a greater understanding of the needs of these families and children.

I am very excited to have recently taken on a brand new role as a Paediatric Cardiac Nurse Specialist two days a week, which will enable families to access this service locally in Cornwall. As this is a new role, we have the unique opportunity to tailor it in the best way possible to create and develop a service that will be of most benefit to families locally alongside the existing Bristol team.

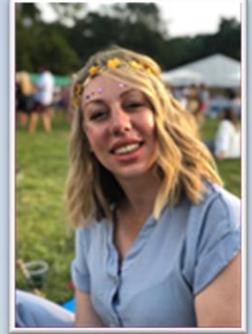
This will be a continually evolving role but the focus initially is on providing support, advice and guidance for families and also to the paediatricians and visiting cardiologists from Bristol. I will also be providing education and support to staff locally. We have just started planning for the set up of a 'transition to adults' pathway - watch this space!"



Continued... the Paediatric Cardiac Service in Cornwall

Gemma Wright, Cornwall's First Paediatric Cardiac Clinical Scientist

Gemma has been working with the team for a number of years developing her congenital experience. The team is keen for Gemma to expand her role to increase capacity and improve echocardiography for all our patients. Gemma has experience and links with the adult team and also supports the adult visiting congenital cardiologists to provide continuity of care for our most complex patients



Tell us a little about your background:

I qualified as a Cardiac Physiologist in 2014 following a four year training position at Worcester Royal Hospital. During my training, I had the opportunity for a placement at Birmingham Children's Hospital. This was my first practical insight into both paediatrics and congenital heart disease. A year later, I was successful in securing the role of Cardiac Physiologist in that same department. My time in a surgical centre was invaluable for learning about congenital heart disease, and the role cardiac scientists play in the diagnosis and follow-up of children with CHD.

Whilst growing up I regularly visited Cornwall and have such fond memories of summers on the beach. When a position opened up within the cardiac department at the Royal Cornwall Hospital, Truro, in 2018, I couldn't resist!



Since moving to Cornwall I have completed the MSc Scientific Training programme to become a Cardiac Clinical Scientist, and gained accreditation from the British Society of Echocardiography in adult transthoracic echocardiography and from the European Association of Cardiovascular imaging in congenital heart disease.



What are you looking forward to?

I am excited to start my new role as a Paediatric Cardiac Scientist in Truro – the first of its kind at a general district hospital in the South West. I am looking forward to working with a fantastic group of forward thinking clinicians, both in Cornwall and throughout the Network to deliver care for our patients close to their homes.

I feel I am in a particularly fortunate position as I will also continue to work within the adult cardiology team, and aim to support the children and adolescents as they continue their journey into adult clinics.



What do you enjoy doing outside work?

I am a keen sea swimmer (in the summer) - the best bit being the post-swim cake 😊



Fun competition time: Name Royal Cornwall Hospital's new ECHO machine

The team in Truro are delighted to have been successful in a bid for a second echo machine. The new machine has arrived and is portable, allowing greater flexibility with inpatient echo for both paediatric and neonatal patients.

This will also increase capacity and the team are planning a brand new initiative to do some outreach clinics around the region (possibly a first for PECs!) to reduce travel time and expense for the Cornish patients.

The team in Truro would like to launch a Network competition to name the new ECHO machine, so do scan this QR code to submit your ideas (or email the Network team). Competition closes end of May 2023.





South Wales Adult CHD Pilot Wellbeing Group

By Dr Anna McCulloch, Lead Consultant Clinical Psychologist in Specialised Cardiac Services,
Sarah Finch, Kindre Morgan, Claire Ormson, Katrina Spielman, Beth Shiers, Clinical Nurse Specialists, South Wales ACHD Services

Facilitated by Down to Earth at the Orchard in University Hospital Llandough, and supported by the ACHD Clinical Psychology and Nursing team, the six session once weekly pilot wellbeing group was attended by 10 adults with CHD.

During the autumn 2022 course, the group members had the opportunity to connect with others and with nature, learn new skills and to challenge themselves.

Having Down to Earth as activity facilitators enabled the clinical psychologist to facilitate both in session and out of session psychological learning and reflection, and enabled the nursing team to support group members and to foster positive patient-healthcare professional team working. All participants completed the course.

Written feedback was gained from 9 participants, and we provide the outcome here. Improvements were reported on social connection, wellbeing, relationships with the ACHD teams, fitness, and cognitions relating to their ability and their health condition.



Wellbeing

8/9 group members reported an improvement in their out of session wellbeing

"Reminded me that I am not just my condition"

"The session has an immediate impact right after the meet and then during the rest of the week. I feel I have a different perspective and look forward to the next"



Shifts in thinking

"Made me more confident about going out and about, and in looking for different ways of doing things"

"I couldn't do the more physical tasks in the group. I was able to do other jobs. This made me look at things differently – I can't do everything but I can do something. It has helped my own lifestyle and mindset"



Value and meaning

"By supporting the developments of the wildlife meadow, I have also felt connected to anyone who may use that facility in the future including others with health conditions, hospital inpatients, staff and the wider community"



Connection to nature

"The group has enabled us to connect with nature and also with the environment around us"



Connection with the ACHD team

9/9 group members felt the sessions improved their relationship with the team

"I feel that this relationship with the team has the potential to reduce stress and anxiety when attending appointments"

"It could also make it easier when times are tough and there may be some bad news that needs to be heard. It's a lot easier to hear this from someone you know a bit better and can be open and honest with"



Peer connection

The group particularly valued the benefits of peer support. They felt connected, valued and understood by each other. They now have a WhatsApp group and plan to continue this support.

"This element has been invaluable for me"

"It has made me realise that I am not alone. I felt valuable. It has been useful to hear other people's experiences and share my own"



Fitness

4/9 group members reported an improvement in fitness, and 6/9 noticed shifts in beliefs about their physical ability

"I used to be afraid to go anywhere on my own and of doing exercise... now I have joined a yoga class and am considering buying an exercise bike"

"I have been able to test myself in what I can do"

What's next? Following the success of the pilot, the team are currently running a new group.



Starting the conversation:

Physical Activity and Exercise in CHD



By Dr Lynsey Forsythe, Cardiac Physiologist and Senior Research Associate in Cardiology
With support from Professor Graham Stuart, Consultant Cardiologist



Physical activity plays an important and beneficial role in long-term cardiovascular and general health. Whilst healthcare providers recognise the importance of promoting physical activity to people with Congenital Heart Disease (CHD), the amount and type of physical activity advice given to patients can vary.

CHD physical activity toolkits

Written physical activity advice is rarely given. However, the recently published range of physical activity toolkits from Heart Research UK can help to start the conversation around physical activity and exercise with your patients leading to more specific and individualised advice.

The toolkits promote physical activity and exercise for people with CHD and comprise of a range of informative resources for patients and families, teachers and sports clubs.

To access these toolkits and for further information, visit the Heart Research UK website:
<https://heartresearch.org.uk/chd-hub/>

The toolkits can be downloaded and are also available as printed booklets which can be distributed to patients and their families in your departments.

A **physical activity recommendations form** can be found in the toolkits to guide your conversation and to record written advice for your patient (these are also available in prescription style pads direct from Heart Research UK).

There are various sections on the form where you can choose from the options provided, such as intensity of exercise recommended (low, moderate, vigorous), amount of physical activity recommended (minutes per day), types of exercise (dynamic, static), activities to avoid (high risk of impact, high risk of injury) and competitive sports (participate fully, participate in some or avoid all).

Current activities, recommended activities and any other comments can be documented in consultation with your patient. The **activity diary** included in the toolkits can be good way to ascertain the frequency, intensity, time and type of physical activity or exercise sessions that your patient is currently doing on a daily or weekly basis. Patients can also document any changes and/or improvements in physical activity participation over time by completing the physical activity recommendations form.

Remember that physical activity comes in many forms and finding activities that your patient will like to do is very important for increasing physical activity participation and also for maintaining this activity over time.



Heart Research UK

This national organisation inspires and invests in life-saving medical research into the prevention, treatment and cure of heart disease, as well as supporting ground-breaking training and education.





A warm welcome

The CHD Network welcome new members

Dr Abdul Salem, Locum Consultant Paediatric Cardiologist with subspeciality expertise in Cardiac Catheterisation and Intervention, and Lead for Paediatric Pulmonary Hypertension at the Bristol Royal Hospital for Children

“Hello! I am new to Bristol, having been trained mostly in London, and am enjoying exploring what this beautiful city has to offer. I subspecialise in Catheterisation and Intervention, and have taken over as link for the Paediatric Pulmonary Hypertension.

Aside from the Cath Lab, I feel most at home on the golf course, and I look forward to sampling the best courses that the South-West has to offer (especially when I visit Cornwall for my outreach clinics!)

I have two young children that keep me busy at weekends. My dream is that they will one day make it to the [Golf] Tour, but my daughter is more interested in picking up the pebbles on the floor than hitting any balls!”



Dr Eva Kapravelou, Locum Consultant
Paediatric Cardiologist

“I am very excited to join the Paediatric Cardiology team at the Bristol Royal Hospital for Children as a Consultant Paediatric Cardiologist with an expertise in Advanced Echocardiography.

My aim is to bring to the team all the latest advancements echo has to offer, but also spread my passion and enthusiasm in making life better for our patients and their families.”



Working together across the Network - In the CHD Network, consultants from Bristol visit hospitals around the South West of England to support the local teams and patients, and consultants from Cardiff visit hospitals across South Wales. This reduces patient travel.



There are a number of changes in the teams across the Network to update you on:

Welcome to the Network **Mary Beadle-Collier**, new ACHD Clinical Nurse Specialist in Bristol, who joined the team in February 2023 and to **Danielle McPeake**, ACHD Clinical Nurse Specialist, who is covering **Hannah Williams'** planned leave at Bristol Heart Institute.

Welcome to **Dr Ines Hribernik**, Locum Consultant in Paediatric Cardiology in Bristol, and **Tony Myers**, new Administrator for the Paediatric Clinical Nurse Specialist (CNS) team in Bristol. Congratulations to **Sophie Slater** and **Zoe Jordan**, who were both on secondment in the Paediatric CNS team and have been recruited to permanent roles within the team.

We would also like to welcome **Jasmine Hughes**, Paediatric Service Manager, and **Roland Gulvin**, ACHD Service Manager, both at the Royal Devon University Hospital. Welcome to **Sam Barrett**, Paediatric Service Manager at Noah's Ark Children's Hospital (Cardiff).

We welcome **Rani Sebastian**, promoted to a Senior Nurse post for Cardiac Surgical Services, and to **Dani Ivan**, Operating Theatres Specialty Manager for Cardiology, both at the Bristol Royal Hospital for Children. We also welcome **Charlotte Revette**, Community Link Nurse..

We bid a warm farewell to **Simon Windeatt**, Service Manager in Exeter, and to **Alison Ficarotta**, in the Taunton Paediatric Cardiology service.

We also said farewell to **Francis Hanlon**, ST7 Registrar in Paediatric Cardiology in Bristol.

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



Congratulations to Dr Victoria North New ACHD Consultant Cardiologist

I am very pleased to have been appointed as a new Locum Consultant Cardiologist with the Bristol Heart Institute Adult CHD team.

I trained at Bristol Medical School, and have been working in hospitals around the South West since I graduated in 2011.

I have worked with the ACHD team at the Bristol Heart Institute since 2018, and also spent 6 months of my Congenital Cardiology training working with the Paediatric Cardiology team at Bristol Royal Hospital for Children. I am delighted to be able to continue working in this service, and with such a fantastic team.

I enjoy teaching and training other health care professionals, and am also very interested in promoting staff wellbeing.

I will be attending the regional clinic in Swindon, and look forward to working with the cardiology team there.

Outside of work, I can usually be found out in the fresh air with family and friends, or playing the piano.

My particular areas of clinical interest are in caring for pregnant women with heart disease, caring for young adults as they transition into adult services, and in palliative care for ACHD patients. I am working alongside Dr Stephanie Curtis in the Obstetric Cardiology Service, and you may meet me in the Cardiac Antenatal Clinic at St Michael's Hospital.

I am passionate about providing high quality holistic care to ACHD patients towards the end of life, and am currently undertaking a Masters in Palliative Medicine at Cardiff University.



Did you know you can find more clinician profiles on your local hospital page on the CHD Network website? <https://www.swswchd.co.uk/en/map>



Education and training



One of the Network's objectives is to support and promote training and education opportunities for our healthcare professionals involved in the care of patients with congenital heart conditions.

Advanced South West and South Wales Adult CHD Training Programme – hosted by Dr Stephanie Curtis

Having commenced in 2009, this exciting programme is back, after a hiatus for COVID-19, in virtual format and commences on Tuesday 25th April 2023. The complete programme runs over three separate days and is intended to cover the entire curriculum of ACHD.

The theme of Day 1 is 'Basic ACHD' and covers septal defects, left sided obstructive CHD, pregnancy, emergencies, non-cardiac surgery, pulmonary hypertension, and how to do an ACHD echo, as well as the role of the CNS and psychologist.

The day is aimed at cardiologists with an interest in ACHD and cardiologists in training, as well as specialised allied health professionals. Speakers include cardiologists and cardiac surgeons from Bristol, Cardiff and London.

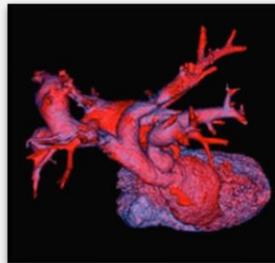


Image courtesy of Dr Nathan

The Annual Virtual Adult CHD study day (autumn) - hosted by Sheena Vernon and the ACHD Clinical Nurse Specialist team

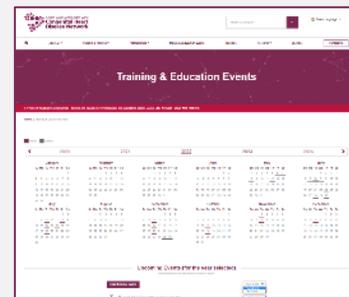


The Network and the Bristol Heart Institute also host an annual ACHD study day that tends to be held in the autumn. This education event is aimed at experienced nurses (adults and paediatric), sonographers, physiologists, midwives and allied health professionals with cardiac experience. It is also appropriate for doctors wishing to gain some initial experience in CHD.

Sheena Vernon, Lead Nurse, (photo on left) has organised these for the last 20 years! Planning is underway for the 21st ACHD study day being held on Tuesday 31st October 2023 –save the date!

What's coming up regionally?

- ACHD training course, part one, 25 April 2023 (Virtual)
- WPCN (PEC) education forum, 12 May 2023 (Cardiff)
- Transition study morning, 18 May 2023 (Virtual)
- Physiologist meet, 23 May 2023 (Virtual)
- Bristol & Cardiff Clinical Nurse Specialist Day, 6 June 2023 (Cardiff)
- Psychology Network Event, 13 June 2023 (Virtual)
- ACHD (annual) study day, 31 October 2023



Visit the Network's [education events calendar](#) for a full list of events. This includes internal education events (regional South Wales and South West CHD Network), with a filter option to view external events related to CHD too. www.swswhd.co.uk



Calling All Paediatric Nurses: 2023 New Webinar Series



The Paediatric Congenital Heart Clinical Nurse Specialist team from the Bristol Royal Hospital for Children have developed a series of educational webinars to support our nursing teams across the Network.

Each 90 minute webinar offers: a teaching presentation, advice and guidance from the Clinical Nurse Specialists, and interactive Q&A at the end of each webinar. The webinars will be available live.

For general enquiries, please email: cardiacnurses@uhbw.nhs.uk

- + Wed 29th March. 10:00-11:30. Normal heart, fetal circulation, and septal defects (PDA, ASD, VSD, AVSD)
- + Wed 12th April. 10:00-11:30. Normal sinus rhythm, common arrhythmias, and anti-arrhythmic
- + Wed 26th April. 10:00-11:30. Prostin dependent lesions (CoA, TGA, severe PS, AS, TOF)
- + Wed 10th May. 10:00-11:30. Hypoplastic right and left hearts; palliative uni-ventricular pathway
- + Wed 24th May. 10:00-11:30. Cardiac failure and medical management





Introducing our new Research Lead Dr Giovanni Biglino



Giovanni Biglino, the new Research Lead for the South Wales and South West CHD Network, is a biomedical engineer and currently Associate Professor of Bioengineering at the Bristol Medical School.

Giovanni studied Bioengineering at Imperial College London and completed his PhD in Cardiovascular Mechanics at the Brunel Institute for Bioengineering.

He has been researching congenital heart disease since 2010, first at Great Ormond Street Hospital/UCL, where he worked as a junior investigator in a Leducq Network of Excellence focusing on modelling single ventricle heart disease and then as a NIHR Research Fellow.

After completing the Global Clinical Scholars Research Training Programme at Harvard Medical School, Giovanni then joined the Bristol Heart Institute/Bristol Medical School, working first with British Heart Foundation Professor Costanza Emanueli (with whom he is still collaborating at Imperial College) and then with British Heart Foundation Professor Massimo Caputo.

Giovanni's research is focused on experimental and computational modelling of congenital heart disease. With invaluable support from The Grand Appeal (one of Bristol Royal Hospital for Children's charities), he established the 3D printing and bioprinting lab currently in the Bristol Royal Infirmary. Some of his research has looked at different applications of 3D models, including to support communication in the clinical setting and to promote patient engagement.

Giovanni is also very interested in interdisciplinary work. He led, together with artist Sofie Layton and health psychologist Jo Wray, a public engagement project culminating in a touring exhibition, The Heart of the Matter. This artistic and scientific exploration of the heart was inspired by patients with heart conditions, their families and clinicians. It invited audiences to discover the extraordinary nature and complexity of the heart through 3D printing, digital animation, sound installation, sculpture and printed textiles, receiving national and international acclaim.



Making the Invisible Visible, by Sofie Layton, image credit: Stephen King

The Heart of the Matter exhibit was defined by The Lancet (academic medical journal) as "a beautiful, thoughtful, evocative representation of what it means to be a patient, a parent, a doctor, or a scientist involved in treating people with heart disease."

He is a board member of the Centre for Health Humanities and Science (CHHS) at the University of Bristol and the co-founder of the Researchers' and Engineers' Alliance for Communication in Healthcare (REACH, www.reach-biotech.org).

The CHD Network are grateful to Giovanni Biglino for taking on this role and are excited to work with him to develop our Network's research strategy for the region. We are looking forward to Giovanni's research updates at the Network Clinical Governance Meetings.



The NHS England standards for CHD require all specialist centres to participate in research.

Research is active and thriving in the South Wales and South West CHD Network, and some of the most cutting-edge research in CHD is taking place in the region.

In 2022/23, over 53 scientific papers were published in high quality peer reviewed journals. These were mainly by Massimo Caputo (pictured below) who is based at the Bristol Heart Institute as a Professor of Congenital Heart Surgery and Consultant in Cardiothoracic Surgery.



Key to the success of any research programme is the participation of patients in studies. Research teams within the Network aim to engage eligible patients in studies so they can continue to drive progress in this field.

Our research teams recruit to studies that are local, national and international in their nature, and charity and commercially funded studies as well as those funded by the government.



Network update

By Louise Hudson, CHD Network Manager

As we emerge from winter it is important to reflect on the challenges the Network's clinical and managerial teams have faced in previous months and recognise the impact on staff, patients and families.

Spring offers us an opportunity to look ahead and consider how we can work together to support everyone involved in delivering and receiving CHD services.

Workplan 2023/24

The Network team is looking forward to working with its members in the delivery of our revised workplan for 2023/24. In response to the issues and challenges highlighted over the past months, we are focussing on projects that we hope will deliver the greatest impact ahead of next winter, including the restoration of some services still adversely affected by the pandemic.

The Network has highlighted projects for the year within a Network 'Plan on a Page'. The projects align to new 'Network functions' from NHSE nationally. You can find our 2023/24 Plan on a Page on the Network website <https://www.swswchd.co.uk/en/page/key-documents>

Network transition project

The transition project is another area of focus, and we are looking forward to supporting the development of more transition clinics like Taunton's (see page 12). When young people move into adult services it is a crucial opportunity to engage with them as shared decision-makers in their health and care. We will be looking at patient feedback and 'lost to follow up' as measures as we gauge the impact of this project.

Patient access

'Was not brought' and 'did not attend' (DNA) are often pre-cursors to 'lost-to-follow up'. Whilst 'NHS-speak' this terminology describes what happens when patients do not access care and miss appointments. The reason vary and are often complex and we want to understand this better so we can enable everyone to make the best use of resources in the coming months.

Network projects

This will be alongside a number of other projects and our usual programme of education, training and events and the Team look forward to engaging with our Network members in a variety of ways.

Do email me at louise.hudson@uhbw.nhs.uk if you'd like to find out more about our work.

Clinical protocols

Did you know that you can access a wide range of clinical protocols via the CHD Network website?

Go to the clinical information page under the professionals tab here:

www.swswchd.co.uk/en/page/clinical-information

A huge amount of collaborative work has happened recently to update and develop clinical protocols for clinicians within the Network. These are available via the document management service and on the Network website.

"The guidelines are incredibly useful. I try, when there is time, to refer to them to always make sure that follow up is as it should be."
(feedback from ACHD Consultant)

Network dates for your diary!

Key Network meetings:

19 April 2023: Network Board

13 July 2023: Network Board and Network Clinical Governance Group

12 October 2023: Network Board and M&M

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



Taunton Cardiology Team Transition Clinics Awarded National Recognition

By Becky Lambert, ACHD Specialist Nurse

The Paediatric Cardiology team at Somerset NHS Foundation Trust received national recognition for their work in setting up transition clinics for young people with complex congenital heart disease in a District General Hospital (level 3 CHD centre).



They won Best Abstract Oral Presentation Award at the British Congenital Cardiac Association – Paediatricians with Expertise in Cardiology Special Interest Group (PECSIG) Annual Conference 2022.

The work was presented by Dr Gangadhara Bharmappanavara (Consultant Paediatrician with Expertise in Cardiology) and Dr Felicity Cooksey (Specialist Registrar) – pictured to the left with Specialist Cardiac Nurses, Becky Lambert (ACHD) and Becky Mirams (Paediatric CHD).

Who is the transition clinic for?

The transition clinic is for young people aged 14-18 years with congenital heart disease prior to moving to adult services. The clinic provides a comprehensive service with consultant review, echocardiography, nursing and youth worker input. The service began in May 2019 and has seen over 50 patients so far.

What team are involved?

The team is led by Dr Ganga Bharmappanavara and includes the Paediatric Cardiology Nurse and the ACHD Nurse, all working in Taunton. The team also includes a visiting Specialist Consultant Cardiologist from Bristol (level 1 centre) and the ACHD youth worker.

Why transition clinics?

Patients learn about practical subjects, including fitness and diet, pregnancy, and employment. The clinic also gives young people and their parents/carers an opportunity to meet the team who will be caring for them in adult services.

Transition care is particularly important for this group of patients as it is crucial that they are not “lost to follow up”. The clinics see young people at a time in their lives when they are gaining independence. It empowers them to take increased responsibility for their care, understanding the intricacies of their condition.

Feedback from patients and their families

Patients and their parents have given positive feedback about receiving care locally and feeling increased confidence having met the Adult Cardiology team.

This service has reduced DNA rates, and patients and families have reported feeling more confident when transferring to the adult service. The team anticipate this will help to improve patient care and achieve better long-term outcomes.



This national event is coming to
Bristol this year!

13th & 14th November 2023

Attendees will be representatives of a
number of cardiac associations, including:

- ♥ The British Congenital Cardiac Association (BCCA)
- ♥ The Paediatricians with Expertise in Cardiology Special Interest Group (PECSIG)
- ♥ Congenital Cardiac Nurses Association (CCNA)
- ♥ British Adult Congenital Cardiac Nurses Association (BACCNA)
- ♥ Congenital Cardiac Anaesthesia Network
- ♥ Non-affiliated healthcare professionals including; Congenital Cardiologists, Cardiac Surgeons, Paediatric Cardiac Nurses, Physiologists and Cardiac Technicians.

This national event is being held at the
Delta Marriott Bristol City Centre.
There will also be a conference dinner!

Registration is open to
healthcare professionals.

<https://cfsevents.eventsair.com/bcca2023/registrationsite/Site/Register>



Cardiac Physiology Services: an example of excellent communication between hospitals on complex cases

By Amy Szewiel, Physiologist

The Adult Echo team at Musgrove Park Hospital in Taunton are lucky to be working alongside Bristol Royal Hospital for Children and the Paediatric Cardiology team in Taunton on a Health Education England funded training programme.

The aim of the programme is to evolve the paediatric and congenital echo services in Taunton and to develop the link with our tertiary centre in Bristol.

The role of the Echo team is to perform and interpret ultrasound images of the heart on new and follow up paediatric patients with a variety of conditions. We perform hundreds of scans every year and work with many specialities not just cardiology patients.

Having good connections with Bristol, our tertiary centre is vital in providing excellent patient care. This was put into practice last year when a young patient attended the cardiology department in Taunton for a routine echocardiogram for chemotherapy monitoring. Some patients receiving chemotherapy require regular scans to ensure the function of their heart remains stable during treatment.

This was performed by the two Cardiac Physiologists involved in the training programme. The echo highlighted an abnormality in the heart, which needed urgent review by a doctor. On completion of the scan, we were able to quickly liaise with the Paediatric Consultant in Taunton and the Echo Lead at Bristol Royal Hospital for Children.

Following an upgrade to our Echo reporting system we can easily share images with the team in Bristol, which has proved crucial to improving this link. Upon review the abnormality was thought to be a blood clot which required further treatment in hospital. Within an hour we held a virtual Teams conference call meeting to discuss the case and a decision was made regarding patient management.

The Oncology and Cardiology teams in Bristol were informed of the findings and the patient was admitted to Bristol the following day and started on appropriate treatment. The patient has since been followed up in Taunton and is doing well.

As a physiologist, knowing that this level of support is readily available is hugely reassuring and gives confidence to perform echocardiograms on a wider range of patients.

From a patient management perspective, being able to have a diagnostic test nearer to home but with the remote support from the tertiary centre will hopefully streamline the entire process and in turn enhance patient experience.



Photo of Amy Szewiel and physiology team in Taunton



Where can you meet cardiac physiologists?

You can often find cardiac physiologists in the cardiology department of your local hospital.



What can cardiac physiologists do for you?

Cardiac physiologists carry out cardiac tests, such as echocardiograms, ECGs, Holter monitors (24-hour ECG), blood pressure measurement, and tilt-table tests.

They may also work in the catheter lab assisting with angiogram and angioplasty procedures, or pacemaker/ ICD implantation.

You will also meet them if you have a pacemaker and/ or ICD, for regular check-ups.

In some hospitals cardiac physiologists are responsible for the long-term monitoring of patients with heart valve disease or replacement valves.



What can you ask them?

Ask them any questions you may have about your test and how it works. Cardiac physiologists are experts in the equipment they use.

Source: The British Heart Foundation website
www.bhf.org.uk



Network Book Club - Read all about it!

Guide for Advanced Nursing Care of the Adult with Congenital Heart Disease

Authors: Serena Francesca Flocco, Hajar Habibi,
Federica Dellafiore, Christina Sillman

The Guide for Advanced Nursing Care of the Adult with Congenital Heart Disease book aims to provide a central resource. It is for nurses, allied health care professionals, physicians and medical technicians who are seeking expert guidance for their practice, regardless of clinical setting, to care for CHD patients from transition to older age.

Hajar Habibi, author and Senior Nurse for the ACHD service at the Royal Brompton and Harefield NHS Hospitals in London shared: "There is a huge gap in the CHD nursing literature. I have been working with an amazing, passionate, and driven team in the past two years to publish this book, to be able to share knowledge and expertise with all who are passionate to care for the CHD patient population as a multidisciplinary team-based approach."

Review by Becky Lambert, ACHD Specialist Nurse in Taunton

"I have worked with patients with congenital heart disease, mainly in a clinic setting, for more than 10 years. During that time, I have undertaken quite a bit of study into the subject, some of which has been ably provided by this Network. However, in that time I have never owned a book on the subject, as there are so many excellent online resources. When I saw this book was about to be published, I decided it was time to change that!

I requested this book for my birthday, which felt slightly "sad" and caused my family some amusement. I am going to be honest here and admit that I haven't read the book from cover to cover but have enjoyed dipping into it.

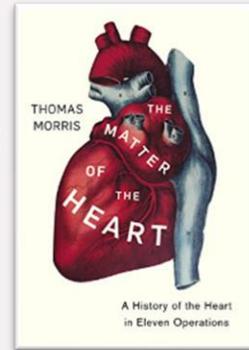


The book starts with an overview of the symptoms, complications, and management of the most common defects. They are clearly set out with good diagrams and a wealth of useful references. There are chapters on such things as care of the patients in both the inpatient and outpatient settings, transition, contraception, pregnancy, exercise and, importantly, end of life care. It appears to be based on up-to-date research and guidance but is easily accessible and patient focussed.

This book champions the important roles of the expert nurse as part of the team caring for this complex group of patients and I think this could be a useful tool, both for individual practitioners and as a resource in many clinic rooms and wards."

The Matter of the Heart

Author:
Thomas Morris



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

"I would thoroughly recommend this book for anyone interested in cardiology, cardiac surgery and the heart in general.

In the mid 18th century it was widely regarded that heart surgery was impossible, and even despite advances in anaesthetic and great advances in surgery in other organs, the heart remained taboo. Respect for the heart can be rooted back to ancient Egypt, where the heart was felt to be the seat of intelligence, emotions and the soul.

The Matter of the Heart is a journey through the marvel of cardiac surgery via eleven operations, starting from the first attempts to operate on the heart and why this was avoided until the mid 20th century. Only in 1944 was the heart successfully operated on internally without the patient dying. Did you know that CPR was not used in resuscitation until 1954!

This wonderful book opens your eyes to incredible pioneers in the field and their risky accomplishments – I can thoroughly recommend the entire book but particular highlights are the Blue Babies chapter (of course) the pacing chapter (particularly interesting to find the first pacemakers were invented in a garage and were plugged into the wall with the inevitable power cut in the hospital causing pandemonium) and the sheer guts and bravery of inventing bypass surgery.

Absolutely one for the collection and a must for every congenital cardiologist."



Staff Photographic Competition #3: 'Birds Eye View'

First
place

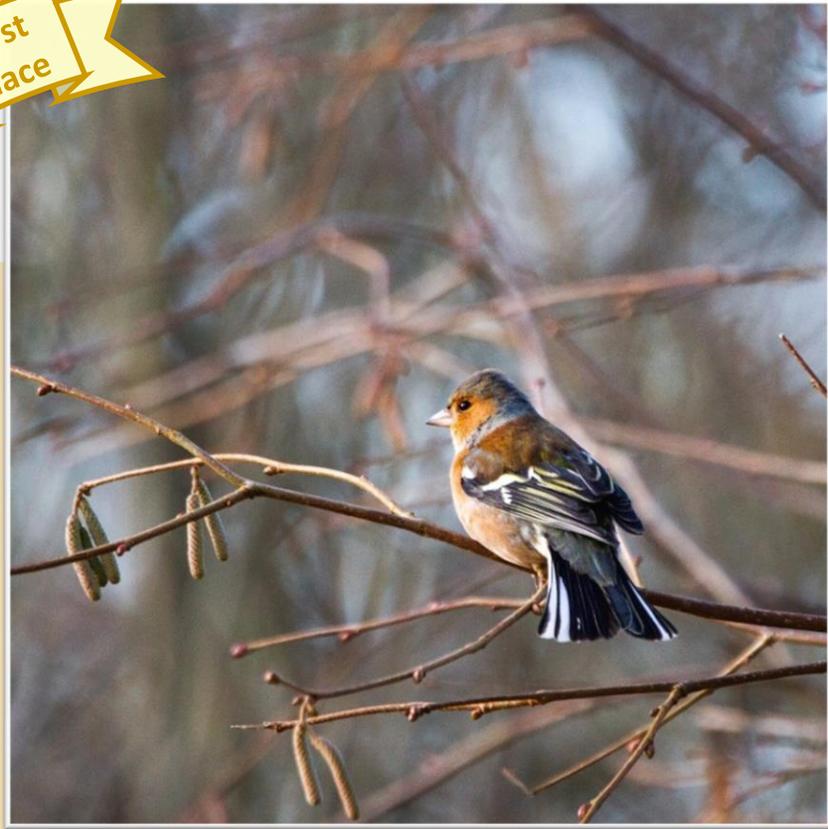
Throughout March 2023 we received many photos from CHD Network staff, who have taken photos whilst out and about, on a trip away or during their commute to work. To see all the entries and also to peruse the galleries of previous entries, please visit the Network website:

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

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



We are delighted to announce that Emma Mugford, Medical Secretary at Swansea Bay University Health Board, is the winner this season with this beautifully captured photograph of a 'male chaffinch waiting his turn for the bird feeder.'



Runners Up



← 'Between the ears...
Chapel Porth to St Ives, Cornwall'

Photographer: **Dr Katy Huxstep**,
Consultant Paediatrician with Expertise
in Cardiology at the Royal Cornwall
Hospital

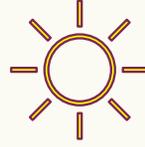
'Keeping a look out in Bigbury, Devon' →

Photographer: **Dr David Mabin**,
Consultant Paediatrician with Expertise
in Cardiology at Royal Devon University
Hospital





Holiday planning



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

It is that time of year again when families start thinking about holiday arrangements. For children with a congenital heart disease (CHD) diagnosis there are some additional factors which need to be taken into account.

Most recent clinic letter

We recommend that all families take a copy of their most recent clinic letter with them on holiday, even if travelling within the UK. If your child needs any treatment while they are away it is important that the team has details of their cardiac diagnosis, and knows who to contact in case of any clinical concerns.



It's also useful to know where your **nearest hospital** will be prior to travelling

Do remember to put in any **repeat prescriptions** early enough so you don't run out of medication whilst you are away.

Travel insurance

This is vital and we recommend you take this out as soon as you have booked your holiday. It is important that you disclose full details of your child's diagnosis and any planned treatments or investigations they are due to have. Families have reported that Marks & Spencer, The Post Office and The Somerville Foundation (for older children) have proved helpful in providing cover for children with a CHD diagnosis.

For children with a complex diagnosis or awaiting investigation

If your child has a complex diagnosis or is awaiting further investigations, then it may be pertinent to check if your consultant has any concerns about your travel plans – you can enquire through the Cardiac Nurse Specialist teams.

For children on warfarin

For children on warfarin, it is important that you give advance warning to the Cardiac Nurses who manage their anticoagulation. If you are travelling abroad, the specialist nurses can provide a letter for the airline regarding carrying the INR testing kit in your hand luggage. They will also be able to provide bespoke advice regarding warfarin management while you are away.

It is very important that you know where the local hospitals will be and that you take sufficient clinic letters/documentation with you in case your child needs medical treatment abroad. You may be required to test your child's INR more frequently, as a different climate and diet may affect their anticoagulation.

We recognise how important it is for families to be able to travel and enjoy holidays. The Clinical Nurse Specialists are here to support you as you make these plans. We are looking forward to the warmer weather hopefully coming soon!

Who are the Cardiac Clinical Nurse Specialists

The Cardiac Clinical Nurse Specialists are a dedicated team of experienced nurses who work with the wider multi-disciplinary teams to provide ongoing information, advice and support to those with a cardiac diagnosis.

The adult and paediatric teams based in Bristol provide ongoing support to patients throughout the South-West, and work closely with the Welsh Cardiac Clinical Nurse Specialist teams mainly based in Cardiff to support patients in South Wales.

CHD Awareness Month February 2023

The ACHD Clinical Nurse Specialists in Cardiff put on many CHD awareness events in hospitals across the South Wales region. Find out more in the team's bitesize briefing on the Network website:

<https://www.swswchd.co.uk/en/page/achd-clinical-nurse-specialist-teams>

This is a photo of Clinical Nurse Specialists Kindre Morgan and Bethan Shiers.





Kal's story

Shortly after birth I was diagnosed with congenitally corrected transposition of the great arteries ("ccTGA"). This means my pulmonary artery and aorta are the wrong way around (transposed) but this is 'corrected' as my ventricles are also switched around - my right ventricle pumps to my body and my left ventricle pumps to my lungs. To add to the mix, I was born with VSD, pulmonary stenosis, and as is common with ccTGA patients, I have Ebstein's anomaly of the tricuspid valve.



Birmingham Children's Hospital looked after me from birth to age 11 but in 1983 I was referred to Harefield Hospital for my first open heart surgery. As I was living and working in London in the mid-1990s my care was transferred to the Royal Brompton (part of the same Trust).

In 2021, I was referred to the Freeman Hospital in Newcastle for a transplant assessment and then added to its transplant list. Also, in 2021 I started to attend my local ACHD centre in Cardiff for IV infusions every three weeks.

The first phase of my CHD journey (1984 – 2007) dealt with 'plumbing' issues. In 1984 Prof Sir Magdi Yacoub operated on me to close the 'hole' in my heart and added a conduit to improve flow between my left ventricle and pulmonary artery. In 2007 Mr Uemura at The Royal Brompton re-did the conduit and replaced my systemic tricuspid valve with a mechanical valve.

The second phase saw me have 'electrical' issues with arrhythmias requiring the implant of a CRT-D in 2010. I had ablations in 2012 and 2014 for atrial tachycardia. Also, in 2014 my CRT-D leads were replaced, and a new pacing system implanted.

The third phase of my CHD journey started in September 2020. While out cycling I suffered a ventricular tachycardia storm requiring eight shocks from my ICD to restore sinus rhythm. After this incident I was diagnosed with significant heart failure.

I was initially assessed for transplant at Harefield Hospital but was not considered a suitable candidate due to my high level of antibodies. The Freeman was asked for their views on ventricular assist device but considered that was not the best way forward. It carried out its own transplant assessment and listed me for transplant on the understanding that I will have a long wait for a suitable donor heart.



Although my CHD journey has been eventful, I have had many successes along the way. Being here to tell you my story is a success, along with looking forward to adding further chapters. To get to here meant I had to work with the fear and uncertainty that comes with having a CHD condition and decide how I wanted to live my life.

Overcoming fear and accepting the uncertainty allowed me to live a full family life, meeting and marrying my amazing wife, Ros, and then with her, raising two fabulous daughters, Milly and Joti. I was also able to pursue a successful full time legal career in London and join the massed ranks of commuters!

Overcoming fear for me meant filling gaps in my knowledge about my ccTGA, talking about possible future interventions and life expectancy so I could understand the physical limitations and psychological issues that impact on my life. This allowed me to take control of it, live with it daily, and manage needing multiple interventions and care from several hospitals.

These successes are built on my family's unconditional love and support. For my part, I have tried to help them manage their fear and anxiety and answer as many questions I can about ccTGA. Difficult and emotional conversations have to be had by being open and honest with each other. Prior to any planned intervention I try to support my loved ones as best I can by trying to reassure them and remain positive. My wife and daughters get to return that support while I am poorly after any procedure by being my advocates and then help me recover and heal. This means we are all part of the process and don't feel alone or isolated.



Continued... Kal's story

Feeling connected to the clinical teams and working in partnership with them is a key component of successfully managing CHD. This connection needs me to be engaged, open and working in tandem with them so they can keep me well for as long as possible. Two-way communication with the medical teams means they see me as a whole person and not just a patient.

A key ingredient to this recipe is the support from Clinical Nurse Specialists (CNS'), who act as a crucial conduit to the clinical teams and psychologists. The CNS' have shown me and my family care and support on so many occasions that I am unsure I can ever properly say 'thank you' to them.

Feeling connected also means spending time with others CHD'ers outside the hospital setting. I was fortunate enough to be a part of the pilot wellbeing group arranged by Dr McCulloch of University Hospital of Wales (Cardiff) and delivered by the Down to Earth team (see page 6).

Meeting and spending time with others outdoors and sharing our experiences meant we could give each other unconditional support and acceptance. This was a very life affirming experience. It reminded me that my CHD worries and anxieties are not unique just to me.



Finally, for me, you can never underestimate the importance of having faith in yourself and the clinical teams to keep you well and to live a full happy and rewarding life.

This photo is of us celebrating after my wife finished the Great North Run last year, raising funds for the Freeman Heart and Lung Transplant Association.

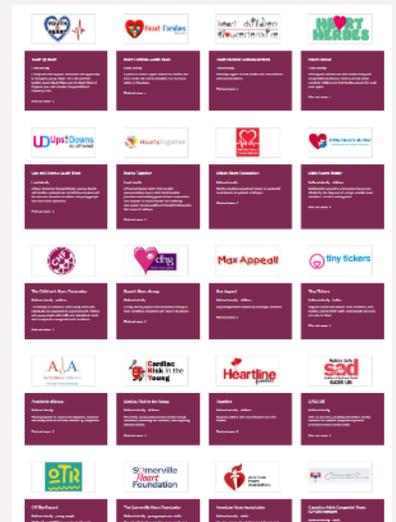
Kal shared his experience of cardiac care at the CHD Network Board in January 2023 – this meeting is attended by staff and patient representatives from across the South Wales and the South West region.

Subsequently, Kal has also been involved in editing the JCC/MDT patient information resources for the Network website, and was involved with the Network patient representative event held in March 2023.

Thank you Kal for your support to the Network!

Charity and Support Group updates

To find about more about the work charities are doing to support patients with CHD and their families, please visit our [charities webpage](https://www.swschd.co.uk/en/page/charities) on the Network website <https://www.swschd.co.uk/en/page/charities>



Are the Cost of Living Crisis & money worries getting you down?

We may be able to help... Somerville Heart Foundation

Attending regular ACHD appointments? Pregnant? Travelling to Transplant Assessments? Our NEW FUND could help towards the cost of travel to appointments

(conditions apply)

For more information on these funds and resources, visit SHF website:

<https://sfhearts.org.uk/news/cost-of-living/>



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: ubh-tr.achdclinicalnursespecialist@nhs.net

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 autumn 2023, 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 is 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