

# Newsletter

Updates from  
your CHD Network

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## Meet our new Clinical Director Dr Stephanie Curtis

### Welcome to the autumn 2022 edition of the South Wales and South West Congenital Heart Disease Network newsletter!

We are delighted to introduce you to our new Clinical Director, Dr Stephanie Curtis.

"I have worked in Bristol since 2002 and as an ACHD consultant since 2008. I have got to know many colleagues around the South West over the years, doing outreach clinics in Truro, Cheltenham, Gloucester and Taunton and liaising with colleagues across the whole region on obstetric cardiology cases.

I was Clinical Lead for ACHD in Bristol for 6 years, around the time the Congenital Heart Disease Network was created and, as a member of the network board since the beginning, I have seen it grow into a mature operational network at the heart of congenital cardiac care and governance in the South West and South Wales.

I am looking forward to working with the rest of the network team in building on the excellent work done thus far and continuing to ensure that high quality care is provided equitably across the region for congenital heart patients of all ages."

What do you enjoy doing in your spare time?

"I am mum to two teenage boys and a cat but when I can I enjoy triathlon and open water swimming but am never too far from a book and a cup of tea."

Find out more about Dr Curtis on the network website  
<https://www.swswhd.co.uk/en/page/who-we-are>



Dr Curtis on the Taunton ACHD team visit

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  
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**Lead Psychologist:** Ness Garratt  
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# Positive news from the Swansea Paediatric Cardiology Team

By Geraint Morris, Consultant Paediatrician / Neonatologist



Back in the 1990s, the local clinical team at Swansea realised that they needed local expertise in paediatric cardiology, so Sheryl, an experienced cardiac physiologist, was dispatched to Cardiff to learn echocardiography in children. She returned to impart her skills, not only in the cardiac investigation of thousands of children in and around Swansea, but to teach echo skills to many others.

Soon Sheryl was joined by Geraint, one of the first consultants to be appointed as a “Paediatrician with Expertise in Cardiology (PEC)”. Together they ran Paediatric Cardiology clinics and provided inpatient cover for babies and children. The cardiac team were then joined by Maha, a neonatologist with cardiac expertise, then Sree, another neonatologist, and again, more recently, by Rachel – yes, you guessed it – yet another neonatologist!



In recent years, the team lacked a general paediatric PEC, and a succession plan for Sheryl’s retirement. The service was then able to appoint 2 excellent trainee physiologists; Carys and then Marian. Carys has recently passed her European Echocardiography Certification, and Marian is at the start of her echocardiography journey.

Emma is our fantastic designated secretary who keeps everything together.

## New Consultant Paediatrician with Expertise in Cardiology appointed

We are also delighted to have appointed Ankita Jain as a consultant paediatrician with expertise in cardiology for the Morriston site (our main inpatient paediatric site) who is starting in November 2022. The service has been well supported both by the local cardiology directorate and by our Children’s Service.

The South Wales and South West CHD Network self-assessment exercise in 2021/2022 really helped form the basis of an effective business case for the new consultant post at Morriston. This post will make a big difference to the care of children with cardiac conditions, as it is the first time a general paediatric “PEC” consultant will be based at Morriston, and the first time children will be looked after by a non-neonatologist.

The team meets every month to discuss ways forward and any issues arising from the service.

## Award winners!

The team has just successfully introduced **ultraportable ECG monitoring devices** (ideal for children), as well as a **new physiology-led clinic**, which has reduced waiting times for the assessment of newborn heart murmurs from 22 weeks to around 7 weeks.

This quality improvement initiative, presented by Carys, was recently given 1st place in the Health Board Quality Improvement Awards. The team is very proud of its achievements and friendly hard-working ethos.

Each clinician makes a contribution to the service. Together the team is a happy, cohesive group, supporting each other to provide a high standard of service for our patients.

We are supported further by tertiary colleagues from Cardiff, whose readiness to advise and assist is invaluable, as well as the SWSW CHD Network.



The cardiology team celebrating coming 1<sup>st</sup> place in the Welsh Health Board Quality Improvement Awards!



## Our Paediatric Cardiac Enhanced Recovery Programme

By Dr Tim Murphy, Consultant Cardiac Anaesthetist,  
Bristol Royal Hospital for Children

In late 2016, the team decided to take a closer look at the way we look after some of our less complex paediatric cardiac surgical patients to see if we could find ways of improving our care for them and achieve some gains in efficiency. This was on the back of increasing evidence in the scientific literature about the usefulness of 'Enhanced Recovery After Surgery' programmes.

Enhanced Recovery Pathways (ERPs) are now common throughout most adult surgical specialties, and they are very slowly gaining popularity in paediatrics.

An ERP has a set of fairly simple, evidence-based recommendations including:

- ♥ Optimising pain management after surgery by using less morphine and making greater use of non-morphine analgesia and local anaesthetic techniques (such as nerve blocks or the increasingly popular 'facial plane blocks')
- ♥ Early mobilisation after surgery
- ♥ Correct intravenous fluid management
- ♥ Proactive treatment of nausea and vomiting
- ♥ Minimising nil-by-mouth periods for food or liquids
- ♥ Proactively managing admission and discharge to try to safely shorten hospital length of stay



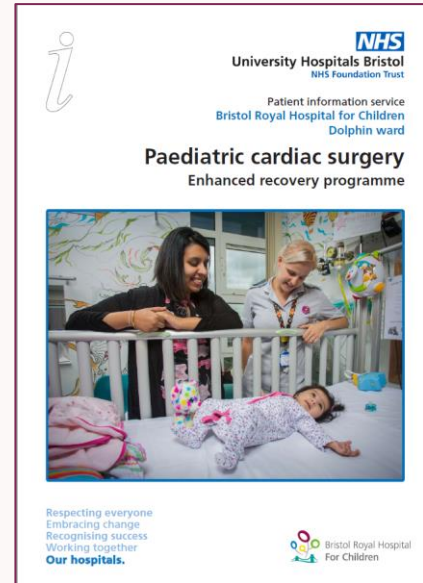
There may also be opportunities, for some patients, to 'prehabilitate' and help to make them fitter for surgery, for example by correcting anaemia or prescribing some physical exercise.

We also had a set of specific milestones for a patient's admission including:

- Extubation within approximately 5 hours from admission to the Paediatric Intensive Care Unit (PICU)
- Discharge from intensive care by lunchtime the day after surgery (ideally, the drains would be removed beforehand)
- Discharge from the High Dependency Unit (HDU) 24 hours later
- Discharge from hospital by the morning of postoperative day 5



In an ideal world, patients would be admitted to hospital in the morning on the day of surgery, but we have found this to be difficult to achieve at this stage, not least because of the size of geographic area which we serve.



Read more about enhanced recovery in the above patient information leaflet on the network website [www.swswchd.co.uk](http://www.swswchd.co.uk)

### In summary, what is the Cardiac Enhanced Recovery Programme?

- It's a research-based pathway for selected patients admitted for cardiac surgery
- It is designed to bring healthcare professionals together and support them in progressing patients along the cardiac surgical pathway
- It promotes excellent care for children and their families, ensuring a smoother and shorter stay in hospital





## Continued... our Paediatric Cardiac Enhanced Recovery Programme

We spent nearly three years preparing for the programme to 'go live' after agreeing for which groups of patients the ERP may be suitable. These were generally otherwise well patients over the age of six months with good heart function undergoing less complex surgery, including some non-bypass cases such as vascular ring surgery.



We put together a **pathway booklet** for each patient and spent time in preassessment clinics discussing the pathway with the patient and their family before admission to Dolphin Ward (cardiology ward at the Bristol Royal Hospital for Children).

Our first ERP patient came into hospital in November 2019 and things went well. We had periods during the COVID-19 pandemic when we were not submitting any ERP patients, but by the summer of 2021 we had reached almost 100 cases, and were able to successfully publish our results in 'Pediatric Anesthesia' in spring 2022 (see reference at the bottom of this page).

Our results demonstrated:



- ✓ Reduction of nearly 20% in PICU length of stay, from around 30 hours to just less than 24 hours
- ✓ Nearly 90% of patients were extubated on time
- ✓ 83% of patients were discharged by day 5
- ✓ Just over 20% of our patients had additional non-cardiac diagnoses or conditions including, for example, Downs Syndrome

We continue to strive to not only decrease PICU length of stay but also hospital length of stay in the future.



### Future plans

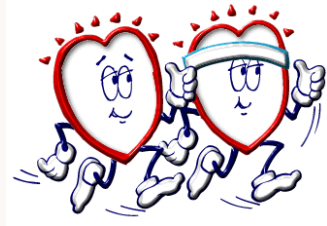
We are looking to build on this initial success, and are already recruiting more patients onto the ERP such as infants undergoing VSD repair or repair of Tetralogy of Fallot. We would also like to formally assess the **experience of patients and families** who have been looked after on our ERP and find ways of improving their experience of care if possible. At this stage, however, the feedback has been positive.

Overall, it has been an extremely positive experience designing and delivering this ERP, with lots of fantastic hard work by all the different teams that provide care to a cardiac surgical patient.



Although other centres in the UK (and indeed across the world) are looking carefully at, or are already doing something similar, **we are the first UK Level 1 Paediatric CHD Centre to publish results of an ERP and we are understandably proud of this.**

Reference Murphy T, Sale SM, Gonzalez Barlatay F, Armstrong C, Parry A, Houghton E, Jerrom T, Schadenberg A. Initial results from an enhanced recovery program for pediatric cardiac surgical patients. Paediatric Anaesthesia. 2022 May;32(5):647-653. doi: 10.1111/pan.14418. Epub 2022 Mar 1. PMID: 35156262.



## Who can go on the Enhanced Recovery Programme?

Currently the ERP is for children over 6 months old (and over 5kg) who are being admitted for less complex and more predictable cardiac surgery.

The decision to be included in the ERP is made at the Joint Cardiac Conference (JCC) when the surgical plan is made, which ensures all key professionals are on board and agreed on the patients suitability.

Examples of surgical inclusions are:

- ♥ Atrial Septal Defects (ASD)
- ♥ Pulmonary Valve Replacement (PVR)
- ♥ Pulmonary Artery (PA) reconstruction
- ♥ Vascular rings / double arch (only if minimal air obstruction)
- ♥ Simple Ventricular Septal Defects (VSD)
- ♥ Left Ventricular Outflow Tract (LVOT) reconstruction





## Read all about it!

# South West Cardiac Obstetric Service

By Dr Stephanie Curtis, Consultant Cardiologist in Adult Congenital Heart Disease, and Obstetric Cardiology

Pregnant women with heart disease have been cared for by a multi-disciplinary team in Bristol for more than 20 years.

University Hospitals Bristol and Weston NHS Trust was one of the first in the UK to see women in a one-stop out-patient clinic setting where they can be seen by several health professionals: cardiologist, obstetrician, anaesthetist, and fetal specialist, and have all the tests they need: ECG, echocardiogram and baby scan. Pre-pregnancy counselling and advice on contraception and IVF is also provided. This successful model has been followed for many years and most centres around the world now aim to provide this type of service.

Though there is an increasing number of women with heart muscle disease, arrhythmias and coronary artery disease being referred to the service, the majority of the women who come to the clinic have congenital heart disease. This can vary from the most simple conditions, such as coarctation of the aorta, to the most complex, such as a Fontan circulation.

The most complex women are not always the most high risk and the risk to the mum and the baby can be different. Both mother and baby are carefully looked after all the way through pregnancy to delivery and postpartum.

Women are seen from all over the South West of England (women from South Wales are seen in Cardiff). The frequency of visits can vary. If they need to be seen very frequently, some of the care can be done in their local hospital under the surveillance of the Bristol team. Delivery of the baby can sometimes be in the woman's local hospital, depending on her risk.

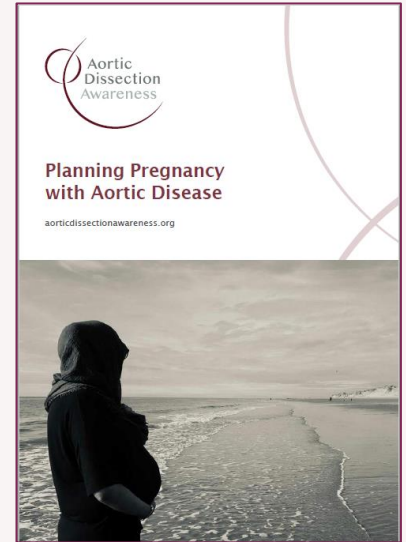
A New Maternal Medicine Operational Delivery Network, based in Bristol, will be established in September 2022 to formalise the pathways that have been in place in cardiology for many years.



As shared in the Spring 2022 edition of the CHD network newsletter, the cardiac obstetric team has recently worked with the artist Sofie Layton on a project funded by Arts Council England.

"Tales from the Ultrasound Clinic" was an installation piece, exhibited in the Bristol Heart Institute in July 2022, and was the result of many hours spent with women with congenital heart disease and their carers.

## Fresh off the press



A new patient friendly **information booklet** (below) has recently been published by the national charity Aortic Dissection Awareness UK. This provides advice for those planning pregnancy with known genetic aortic diseases, such as Marfan syndrome and Loeys-Dietz syndrome.

This booklet was put together by Dr Stephanie Curtis and Haleema Saadia, who suffered an aortic dissection in her pregnancy and underwent several operations whilst pregnant. It aims to educate women about the risks involved in undergoing pregnancy with aortic disease in the hope that this will reduce the risk of dissection and also empower women to make decisions around pregnancy and birth.

This booklet can also be found on the network website [www.swswhd.co.uk](http://www.swswhd.co.uk) and the national patient charity's website [www.aorticdissectionawareness.org](http://www.aorticdissectionawareness.org)





## Staff Wellbeing and Support

By Dr Alice Walker, Clinical Psychologist, Healthier Together Support Network

Working in healthcare often involves supporting people facing very difficult experiences. Day-to-day work always has potential to be challenging. The last two years have brought even greater uncertainty and pressure to the jobs we do.

If you or your team are struggling, it can sometimes feel overwhelming to work out how and where to access the right support. Psychological support can provide a space to reflect on our own needs, which we can often end up neglecting when working in highly pressured environments and providing care for others.

### Accessing psychology support



Wherever you are based, there is likely to be a range of options for staff to access psychological support, both as individuals and teams. A good place to start is **your local health and wellbeing hub**.



Many of these services have been established over the past year, and offer a self-referral for health and care staff to access a variety of support. For example, in the Healthier Together Support Network (HTSN) covering Bristol, North Somerset and South Gloucestershire, staff can access 1:1 assessment and therapy and a range of training, workshops and webinars on topics such as workplace wellbeing, caring for ourselves to care for others, coping with traumatic events at work, and connecting with nature for wellbeing.

More information about the support service for your area can be found at:

- South West England: <https://www.england.nhs.uk/supporting-our-nhs-people/support-now/staff-mental-health-and-wellbeing-hubs/south-west-hubs/>
- Wales: <https://heiw.nhs.wales/support/colleague-health-and-wellbeing/>

Support comes in many formats, and there are many ways to start building your own psychological 'toolbox' in your daily life. A couple of strategies to use at times when life can feel overwhelming, uncertain, distressing, or just to bring a moment of calm to your day are:

### Grounding

Our senses can provide a way to return to our present moment, to ground ourselves in the here-and-now. The '5-4-3-2-1' technique is a simple grounding strategy that you can do anywhere. It's a lovely exercise to try outside, bringing additional wellbeing benefits of connecting with nature.

- 5 – Look around and name 5 things you can see
- 4 – Notice 4 things you can hear
- 3 – Feel around for 3 things you can touch
- 2 – Become aware of 2 things you can smell
- 1 – Notice 1 thing you can taste



### Safe place imagery

The images in our minds can have a huge influence over our emotions, so imagining safe and calming places can effectively soothe feelings of threat, vulnerability and anxiety. The HTSN has published a podcast about using safe place imagery, including a five minute guided imagery exercise, which is freely available to listen to or download at:

## Getting into nature: New ACHD wellbeing group pilot for patients and staff

By Dr Anna McCulloch, Lead Consultant Clinical Psychologist in Specialised Cardiac Services, University Hospital Wales (Cardiff)

The South Wales ACHD team are currently piloting a wellbeing group based in the Orchard at University Hospital, Llandough.

The group is facilitated by Down to Earth as part of a Cardiff and Vale NHS initiative and two members of the ACHD team attend to support group members.

The six week programme gives group members the opportunity to be in nature, to connect with each other, to learn new skills and to contribute to the upkeep of the Orchard site.

We are half way through the programme and people report the group has a positive effect on their wellbeing and has improved feelings of social connection. We as an ACHD team also appreciate this opportunity to learn from group members.



Sarah Finch, ACHD Clinical Nurse Specialist, with Frankie, patient representative.



## Lifespan Psychology Update

We are delighted to introduce three new members of our team across the South West of England and South Wales. In our ACHD service we have Pauline Aiston (Bristol) and Ellen Huish (Cardiff) and Kathryn Thomson in our paediatric service in Bristol. Below is a brief hello from of our new starters.

Welcome! 😊

### Adult CHD psychology services

#### **Pauline Aiston, Chartered Health Psychologist, Bristol Heart Institute**



"I am delighted to have started this new full-time permanent psychologist role in July 2022, at the Bristol Heart Institute Level 1 specialist Adult Congenital Heart Disease (CHD) surgical centre. I work in collaboration with psychologists in the paediatric cardiology service, to offer psychological support for individuals with CHD. I'm delighted to be joining Ellen and Anna in developing the Adult CHD service across the South Wales and South West CHD network.

My background: I have gained a wide range of experience whilst working in the NHS - from community and hospital based mental health services, to more recent times working within a range of physical health specialities: pain self-management, chronic fatigue, motor neurone disease, cancer and palliative care and respiratory."

#### **Ellen Huish, Clinical Psychologist, Cardiff**



We are delighted to welcome Ellen into the Adult CHD service in Wales. Ellen has recently completed her final placement for the clinical psychology training in the paediatric cardiac team in Bristol so we are hugely excited to see her start her career in our cardiac network.

Ellen works with **Anna McCulloch** (photo on the right) in Cardiff! We welcomed Anna in the Spring 2022 newsletter. This is a new service thanks to a successful national business case that released funds to enhance the Adult CHD service in Wales.



### Paediatric CHD psychology services

#### **Kathryn Thomson, Clinical Psychologist, Bristol Royal Hospital for Children**



"I am Kathryn and I'm very excited to be joining the paediatric cardiology service in October 2022 as a clinical psychologist. I have worked for the NHS since 2015 and am passionate about helping children and families impacted by health conditions to live happier lives in line with their values. I am looking forward to getting to know everyone in due course."

Kathryn will be joining our Network Psychology Lead, Vanessa Garratt. (photo on the right)







## Next steps to developing our service: Improving access to psychology support

By Vanessa Garratt, Consultant Psychology Lead

We are reviewing our website to make it easier for families, adults and clinicians to find out about support options and how to access our teams. We are revising our Adult CHD leaflets with your help to provide better information about accessing support and now have a range of paediatric QR code posters to help you find the resources and webinars to help you.

### Quality of patient care

We will be looking at how we can find out more about your experience of our care in the next year and the quality of the care we offer. We are also creating templates for support plans that we can work with you on and you can use at home to take to your teams, as well as improving our inpatient information on what to expect when preparing for an admission.

### Psychological training and education for clinicians

We want to continue to develop the training we offer to staff in the next year and will continue to offer bitesize training to help develop psychological skills in our staff teams and work with you to look at what training we need to develop. We will be offering presentations to our network teams on psychological care. This includes the transition study day and supporting our clinical teams with supervision.

We continue to feature on our network website our toolkits and leaflets on how to access support, as well as posters in our hospital settings.

<https://www.swschd.co.uk/en/page/getting-support>

South Wales and South West  
**Congenital Heart  
Disease Network**

University Hospitals  
Bristol and Weston  
NHS Foundation Trust

**Wellbeing Resources for Children & Young People  
During Admission on the Ward**

Coping as a teenager with having an illness

I'm worried about having a medical procedure

Coping as a teenager in hospital and going home

I'm having trouble sleeping

I'm transitioning to adult services

Managing difficult feelings

What can I do if I feel worried or low

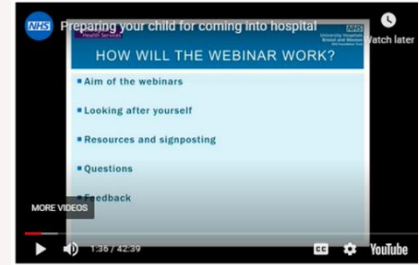
To use the QR codes  
1. Open your device's camera or download a free QR code reader  
2. Point your camera at your chosen QR code  
3. The link should open up as a pop up!  
Try it on the code to the right to visit the SWSW CHD Network website.

## New patient and family wellbeing QR code posters now available!

The aim is to have the QR code posters displayed in services across the network, for example:

- In outpatient departments for parents to access freely
- In clinic rooms for parents to be directed to by clinicians
- On the ward for admissions

The posters can be downloaded from the network website



### New online webinar series

The paediatric cardiology psychology webinar series 'Living with a Cardiac Condition' is now available on the CHD network website!

[Psychology Webinar Series - Living with a Cardiac Condition \(swschd.co.uk\)](https://www.swschd.co.uk/psychology-webinar-series-living-with-a-cardiac-condition)

There are four webinars that can be viewed on demand:

- Managing the impact of a having a child with a heart condition, for parents
- Supporting siblings of a child with a heart condition
- Supporting your child coming into hospital
- Mindfulness.

New 'Tips and tricks ACHD inpatient leaflet' written in collaboration with the network patient representatives – now published on network website.

University Hospitals  
Bristol and Weston  
NHS Foundation Trust

Patient information service  
Psychological Health Services

**Tips and Tricks for Managing on the Ward for Adult Congenital Heart Disease Patients**



## Education and training

One of the network objectives is to support and promote training and education opportunities for our healthcare professionals. During the COVID-19 pandemic, the network has been able to deliver a variety of programmes of education and training online.



### 2022 Virtual Adult CHD study day, October 2022



Over 100 healthcare professionals from across the region and beyond attended this free online study day that covered a variety of ACHD topics. The themes of the day were right sided heart lesions, Ebstein anomaly, tricuspid atresia/fontan and pulmonary atresia.

The study day was aimed at experienced nurses (adult and paediatric), sonographers, physiologists, midwives and allied health care professionals with cardiac experience, as well as being appropriate for doctors wishing to gain some initial experience in this area.

*"Thank you for a well organised and informative study day –such a good mix of CHD topics to enhance the knowledge of a range of staff groups across the region"*

*"The range of speakers was brilliant."*

### Adult & Paediatric CHD Clinical Nurse Specialist Away Day (Cardiff), June 2022

This away day for the Cardiff and Bristol CHD Clinical Nurse Specialists included each team sharing their 'highs, lows and good to knows', as well as a session led by a consultant leadership coach.

*"A brilliant session. Nat was so passionate and engaging. I learnt a lot that I can apply both to my professional and personal life. Really inspiring!"*



The next CHD network clinical nurse specialist away day in November 2022 is being held in Bristol.

### Fetal Cardiology for Sonographers training day, Bristol, October 2022



The hybrid programme was full of presentations, discussions and networking opportunities, aimed at sonographers, and anyone wishing to improve their knowledge of the fetal cardiac anatomy and skills in scanning the fetal heart.

The day included talks on normal fetal cardiac anatomy and the most common cardiac abnormalities presented by members of the fetal cardiology teams from Bristol and Cardiff, an update from the clinical nurse specialists on managing cases; as well as a patient perspective on their journey from suspicion of a cardiac anomaly through to diagnosis and their onward journey through the fetal cardiology service.

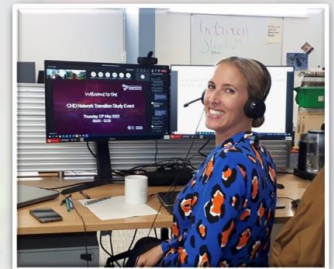
*Thank you to all those  
involved*

### Transition study events, May & October 2022

The first event was held in May 2022 with over 33 participants from across the network and beyond. This focused on adolescent behaviours, HEADSS assessment tool, and mental health.

The second event was held in October 2022, which focused on CHD and transition care covering pregnancy risk, drugs, alcohol, exercise and much more.

Both sessions were really well evaluated and successful. We are so grateful to our specialist speakers for their excellent presentations.



### News from the South Wales ACHD Clinical Nurse Specialists

Now recruiting... ACHD Link Nurses!

We are offering the exciting opportunity to join our group of ACHD link nurses across South Wales! We offer continuous support, education and hold bi-annual study days empowering the care and support of ACHD patients. If you are interested in becoming a link nurse, get in touch!

### Teaching Boards

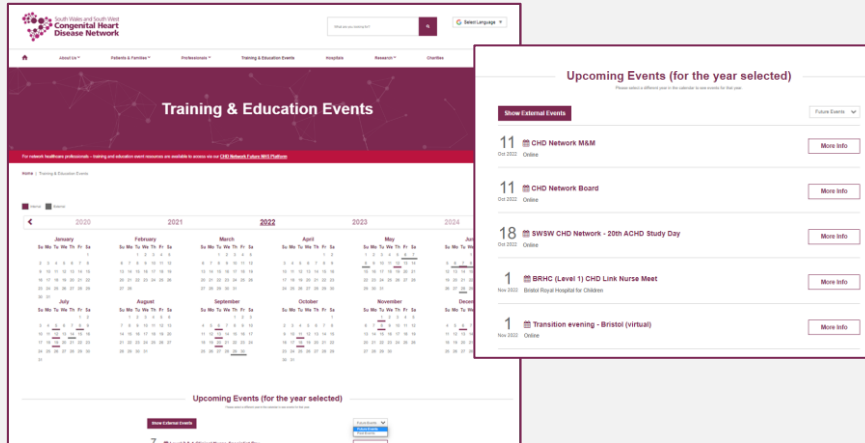
With the support of our link nurses we will be regularly updating our teaching boards in clinical areas. Keep a look out for a teaching board near you!





## New events calendar on the network website!

In May 2022, we launched a [new education events calendar](#) on the network website. This lists internal education events (regional South Wales and South West CHD network), with a filter option to view external events related to CHD too.



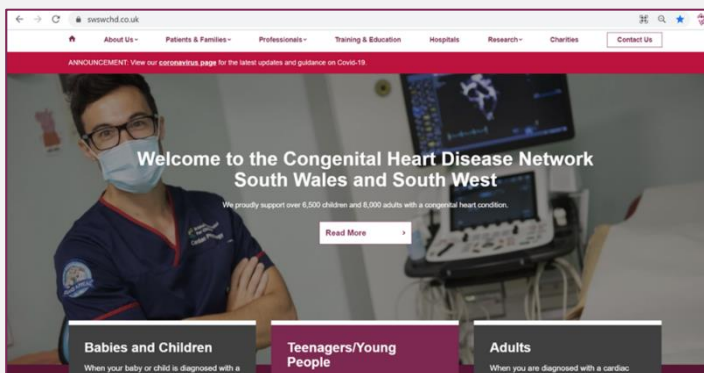
The aims included:

- ✓ Increasing the visibility of events
- ✓ More user friendly/professional/clear look
- ✓ Calendar underlines event dates – internal network events (colour coded in our network purple), and external events that may have a general interest to the CHD network (colour coded in grey)
- ✓ Preview list of upcoming events (located below the calendar) – internal/external events filter function.
- ✓ Users can click on ‘more info’ for a pop-up info page outlining details of the event
- ✓ A filter function is also available to view ‘past events.’



Let us know your views! Please send the core network team your feedback, or other CHD related events that could be of network interest to add to the calendar. This is a work in progress, and the aim is for this to be as useful a tool to network members as possible.

The [network website](http://www.swswchd.co.uk) ([www.swswchd.co.uk](http://www.swswchd.co.uk)) includes a range of resources for staff, patients of all ages, and their families, which are being continually added to and updated.



### What’s coming up regionally?

- WPCN (PEC) education forum, 24 November 2022 (Cardiff)
- Level 1 & 2 Clinical Nurse Specialist Day, 29 November 2022 (Bristol)
- Physiologist meet, 6 December 2022 (Virtual)
- South West Paediatric Cardiology Forum, 20 January 2023 (Virtual)
- ACHD training course, part one, 25 April 2023 (Virtual)



### SWSW CHD Network NHS Future Platform

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

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

Over 200 healthcare professionals have already signed up and are using the platform.

To register please email [SWalesSWCHD-manager@future.nhs.uk](mailto:SWalesSWCHD-manager@future.nhs.uk)

Once registered as a member, the link to sign in is

<https://future.nhs.uk/SWalesSWCHD/group>



## My Clinical Observership in Paediatric Cardiology & Surgery in CHD

By Andrea Nizzoli, undergraduate student

### About me

I am Andrea and I'm 22 years of age. I am an Italian medical student who lives and studies in Verona (where Romeo and Juliet by Shakespeare is set, you know?). This time my desire to learn brought me to the Paediatric Cardiology department at the Bristol Royal Hospital for Children.

### Summer work experience

People around me often tell me that I'm talented, but I know that talents are not enough: commitment, dedication and personal initiative are needed to achieve your goals. That's why I am investing my holiday time to go deep into a discipline that is not included in the regular path at university in Italy.

I finished the exams earlier than anyone in my course, been studying 10-12 hours everyday for the last 5 months, in order to be here over my summer holidays. I am so grateful to Dr Davide Marini (Consultant Cardiologist), to the Bristol Royal Hospital for Children and to the University of Bristol for giving me this opportunity.

### How did this come about?

Studying medicine I started to love the heart: it's such a magnificent organ! Last year, when I was looking at the cardiac embryology, I discovered some articles about paediatric cardiology by Dr Marini. They were so interesting and I knew that in Verona there isn't a Children's Heart Centre, so I decided to ask Dr Marini to an observership in paediatric cardiology in Bristol would be possible.

I would like to improve my knowledge in the paediatric heart, diagnostics and in surgery, as well as research. I think that this experience will help me find the right way in the medical field, opening new horizons and allowing me to meet a lot of different professional profiles with their personal stories and suggestions.

This is a great opportunity for me and I want to enjoy this chance that will be so important in my medical training.



Congenital Heart Disease e-learning for Health modules launched in May 2022.

The target audience includes all health professionals who may encounter CHD patients but are not specialists in this area (including GPs, midwives, health visitors).

Three modules have been uploaded so far to enhance knowledge of cardiac care:

- ✓ Overview of CHD
- ✓ Introduction to neonates and infants with CHD
- ✓ The ACHD patient

Find out more at [e-lfh.org.uk](http://e-lfh.org.uk)



The BCCA Annual Conference 2022  
in Birmingham on  
7<sup>th</sup> & 8<sup>th</sup> November

<http://bcc2022.co.uk/>





# Welcome

## Meet Louise Hudson, our new CHD Network Manager!

We were delighted to welcome Louise to the South Wales and South West CHD Network in September 2022.



### Tell us a little about your background

After graduating from Manchester University, I began my career working in the health and social care voluntary sector in London. I moved to Bristol with my young family just in time to see in the millennium. There followed a balancing act of family-life, study and work in partnership, development and communication roles with local government, the voluntary sector and the NHS.

On completion of an MSc in Public Health in 2013, I joined Bristol, North Somerset and South Gloucestershire's (BNSSG's) Clinical Commissioning Groups (CCGs) as Partnership Manager prior to the merger of the three organisations.

Following this organisational change, I worked with general practice and local organisations as a Locality Development Manager for the CCG before taking up a secondment in 2021 as an End-of-Life Care Project Manager. Working in this role with clinicians passionate about their field of expertise, I was inspired to seek a more permanent role aligned to a clinical speciality.

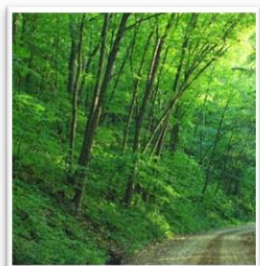
### What are your interests/passions?



I bring with me a continued interest in health's wider dimensions and enjoy working closely with clinical colleagues and those in allied roles, at all levels, as well as with patients and carers. I strongly believe everyone has a role to play in the development of services.



### What do you enjoy doing outside of work?



Outside work, I love spending time with family and friends. I have three children and with only one living at home full-time now, my nest empties and fills on a regular basis.

I live on the edge of an ancient wood and spend a lot of time walking there as well as gardening, reading and listening to and sharing music and podcasts.



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

Welcome to the network Dr Maria Velasco Forte, Consultant in Paediatric Cardiology in Bristol, who joined the team in July 2022. Congratulations also to Dr Ankita Jain, in her new appointment as Paediatrician with Expertise in Cardiology in the Swansea Bay Health Board.

Welcome to Karina Howell, new part-time Transition Clinical Nurse Specialist in Cardiff, and to Josie Wharton-Bailey, voluntary ACHD Link Nurse at Gloucestershire Hospitals.

We would also like to welcome Pauline Aiston, ACHD Clinical Psychologist at the Bristol Heart Institute, Ellen Huish, Clinical Psychologist in Cardiff ACHD team, and to Kathryn Thompson, Paediatric Clinical Psychologist in Bristol.

At Musgrove Park Hospital, we welcome Sarah Davies, new Services Manager covering paediatric CHD. We also welcome Haylee Pike, new Service Manager covering Swansea Bay paediatric CHD service, and Zoe Cliff, new Service Manager covering the Gloucestershire paediatric CHD service.

We bid a warm farewell to Dr Andy Tometzki, as he stepped down as network Clinical Director after 6 years in the role – thankfully Andy is not going far and has successfully taken up the role of Clinical Lead for paediatric cardiology in the level 1 centre. We congratulate Dr Stephanie Curtis on her appointment to the network Clinical Director role.

We also said farewell to Joe Mills, Service Manager in Gloucestershire, to Emma O'Connell, Service Manager in Taunton, and to David Withers, voluntary ACHD Link Nurse in Gloucestershire. Thank you for your support and commitment to your local CHD services and to the network.



## Staff Photographic Competition #2: 'Summer scenes across the network'

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

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

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

**Winner**

We are delighted to announce that **Ankita Jain, Consultant Paediatrician with Expertise in Cardiology, in Swansea, Wales**, is the winner with this spectacular double rainbow captured over beautiful Swansea Bay.



**Runners Up**



'A sunset swim is always good for the soul!  
New Quay Beach, West Wales

Bethan Shiers  
ACHD Clinical Nurse Specialist, South Wales



'Bristol Harbour sunset'

Steven Pike  
General Manager, Bristol Royal Hospital for Children

The staff competition will open again ahead of the spring newsletter – we look forward to seeing your creative images!  
For further information please contact the CHD network team via [Rachel.Burrows2@uhbw.nhs.uk](mailto:Rachel.Burrows2@uhbw.nhs.uk).



## Network update

By Louise Hudson, Congenital Heart Disease Network Manager, South Wales and South West

Coming into role this September I was struck by how much has been delivered by and for the network over the past six months. Delivery and promotion of events and education programmes continued a pace despite a smaller staff team.

These included link nurse and physiologist meetings, a Paediatricians with Expertise in Cardiology forum and bite-size monthly education initiatives for nurses. One of the first events I attended was a transition study event led by our Lead Nurses, Jess and Sheena, and featuring many experts including youth workers and physiotherapists.

In the last issue of the newsletter, you heard from my predecessor John Mills about an important piece of work to support CHD services in South Wales to complete a self-assessment against NHS England CHD standards. With the report now finalised and due to be presented in December 2022 we are looking forward to continued collaboration with colleagues in Wales to support action against the findings.

I was delighted to attend the network's Board meeting in October where we heard from a patient, Tom Large. Tom shared his experience of surgery and care, reminding us of the importance of good communication. Communication was a theme which was repeated often throughout the meeting, and we discussed how we could improve communication with patients and families waiting for care.

When we communicate well, we do our best work, and this is demonstrated by the fantastic psychology wellbeing QR code posters designed in recent months for parents, carers, children and young people. Rachel, our Support Manager, has also updated the charity and support groups website pages and refreshed and redesigned the 'Information for Adults' patient support page on the network website, with support from the ACHD Clinical Nurse Specialists.

Published over the summer, the Annual Report provides us with an opportunity to communicate what we do as a network, highlighting successes and challenges. Have a look because as we approach the end of the year we will be reviewing our workplan for 2022/23 and drafting our work plan for 2023/24 and are interested in your views on future priorities.

I also want to take this opportunity to thank everyone involved in welcoming me into my role, including our outgoing Clinical Director Dr Andy Tometzki and incoming Clinical Director Dr Stephanie Curtis. During my orientation I have met many inspiring people working in CHD across the region as well as patients and carers and hope to meet many more of you over the coming months.

Do contact me at [louise.hudson@uhbw.nhs.uk](mailto:louise.hudson@uhbw.nhs.uk) if you'd like to introduce yourself!

### CHD Network 2021/22 –

Read all about it!



The Congenital Heart Disease Network Annual report for 2021/22 has been published.

Find out about the key achievements and challenges for the network in its sixth year of operation, and the key priorities for future years.

Thank you to all the network members who have contributed to this fantastic update on progress this past year. Please visit our network website ([www.swswhd.co.uk](http://www.swswhd.co.uk)) to read it in full.

### Network dates for your diary!

#### Key network meetings:

**19 January 2023:** Network Board &

Network Clinical Governance Group

**19 April 2023:** Network Board

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



## Kate pedalled all the way From Bristol to Rome

By Kate Sykes

Arriving at the Colosseum in Rome on our fully laden bicycles felt surreal and emotional. My partner Gary and I had cycled 1804 miles in 59 days from Bristol UK, and had finally arrived at our final destination. With tourists milling around us, the reality of our journey finally came together.



The ride had taken us through seven different countries. We had woven our way through London on our way to Calais, cycled for days on dreamy traffic free cycle routes through France, Belgium and Luxembourg, pedalled along the Rhine in Germany, climbed 2108 metres to the San Gottard pass in Switzerland, and rattled our way along the Strada Bianche tracks in Italy.

We had drunk coffee in beautiful French villages surrounded by vineyards, camped in forests and by lakes and halfway up mountains and met strangers who went out of their way to accommodate and help us on our journey.

Our bikes were heavy with camping gear, a stove and enough homemade dehydrated food to be largely self-sufficient. It was, at times, challenging, with the heat in August forcing us off the road. Crazy Italian driving left us reconsidering our onward trip after being passed one too many times, far too closely and quickly.

One of the additional challenges in this ride is that I was born with the heart defect Tetralogy of Fallot. After my operation at the age of three, I have lived a pretty normal life. But I have severe to moderate pulmonary regurgitation, an enlarged right ventricle wall and in future will need a new pulmonary valve. It was important not to put too much pressure on a heart already working harder than it should. So we had to plan quite carefully around this.

Our plan involved travelling around 40 miles a day and taking rest days on every fifth day. I sought out a final thumbs up from my Cardiologist Dr Stephanie Curtis. One of the main restrictions to exercise for me is that at 125 to 135 bpm, my heart starts to miss beats and can go into the arrhythmia 2:1 block. When this happens, my blood pressure drops and the heart rate almost halves, preventing me from continuing to exercise until it rights itself.

The journey over the Alps was my biggest concern and meant 23 miles of almost continuous climbing to a height of 2108 metres. Lugging 23kilos of gear and going steeply up hill made it hard to keep my heart rhythm low. It was an intense experience, pedalling very slowly and gently, whilst monitoring my heart rate constantly with a heart monitor strap and watch. I stopped regularly to let my heart rhythm reduce and give my complaining legs a break.

The feeling of arriving at the top was incredible, I don't think I had quite realised how worried I had been about the climb, and the relief, joy and pride in myself was overwhelming.

Managing my heart condition was just one part of an incredible ride; it in no way defined it. With careful planning it became a part of the experience. An experience that will keep giving for many years to come.







# Cardiac Surgery Charity Trip to Romania

By Frances Greaves, Staff Nurse

At the end of August 2022, a team of healthcare professionals from across the UK and Europe came together for a week to support the cardiac hospital in Timisoara in Romania in developing their paediatric congenital heart disease programme.

At the hospital both international and local teams worked in partnership across language and cultural barriers to enable 7 children to have open heart surgery and also a number of children to have surgery via cardiac catheter.

The nursing teams were involved in supporting the current Romanian team (experienced adult cardiac nurses) care for children post cardiac surgery.

The main learning points we focused on were removal of pacing wires and chest drains, and managing intravenous and enteral fluids. It was a learning experience for everyone. The hospital had fewer and different resources and medications so we had to adapt our usual care and think outside of the box.



Working with a medical team made up of professionals across the UK and Europe was both challenging, due to the differences in practice. It also made it a great experience for discussion about evidence and ideas surrounding the care of children post cardiac surgery.

The first patient to have surgery was a 4 year old girl who had an atrial septal defect repair. It was great to follow her progression post-op to the point of nearly being ready for discharge at the end of the week.

She experienced some bumps along the road when she developed fluid around her lungs. However, it was lovely to see her towards the end of the week doing a lot better and walking around the paediatric ward and playing with her surgeon Barbie doll.



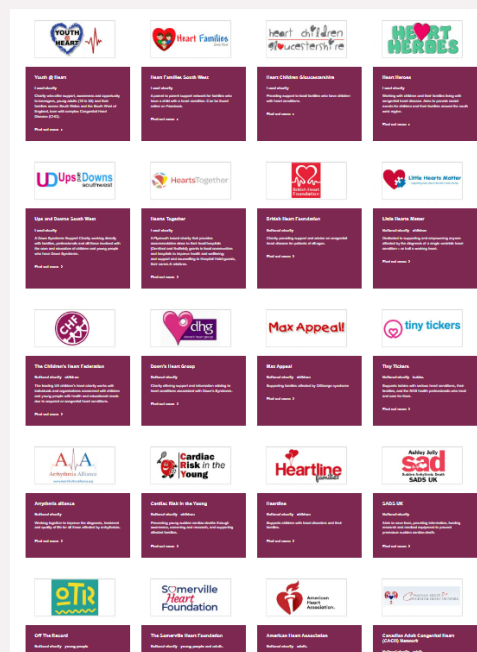
This trip was supported by charity Healing Little Hearts  
<https://healinglittlehearts.org/>



## Charity updates

To find about more about the work charities are doing to support patients with CHD and their families, please visit our newly refreshed charities webpage on the network website

<https://www.swswhd.co.uk/en/page/charities>



Revealing the facts – Atrial Septal Defect

Find out more about this heart condition on the British Heart Foundation website:  
<https://www.bhf.org.uk>



# News from the Bristol Paediatric Cardiac Clinical Nurse Specialists



By Jo Bailey, Paediatric Clinical Nurse Specialist

## Who we are

The paediatric cardiac nurses are a dedicated team of experienced nurses who work with the wider multi-disciplinary team to provide ongoing information, advice and support to children and their families with a cardiac diagnosis.

Although we are based within Bristol Royal Hospital for Children, we provide ongoing support to patients throughout the South-West, and we work closely with the Welsh cardiac nurse specialist team based in Cardiff to support patients in South Wales.



## Staffing updates


We are delighted to announce that **Lisa Patten** has been formally appointed as Team Lead. Congratulations to Lisa for receiving formal recognition for the role she has performed expertly over the past 5 years! We are currently in the process of recruiting for a full time band 7 and band 6 CNS as well as a new administrator.

We are pleased to welcome back **Beth Brock** and **Sophie Morland** from maternity leave. Earlier this year, we said a sad farewell to two long-standing colleagues. **Diane Barlow** is now working with the Adult Inherited Cardiac Conditions Team at the Bristol Heart Institute, and **Jess Hughes** has left to work permanently with Sheena Vernon as Lead Nurse for the CHD network. We will miss their wealth of knowledge and wish them well in their new roles.

See the back cover 'useful contacts' for details of how to contact the CNS teams


## Paediatric Dental Pathway Audit

**Zoe Jordan**, who is currently on secondment with our team, has completed a comprehensive audit of our dental pathway. The gold standard is that children over the age of 6 months, whose teeth have come through, receive an appropriate dental check prior to being listed for cardiac surgery. The aim of this being to reduce the risks of endocarditis (infection of the lining of the heart).

 Find out more - British Heart Foundation endocarditis information: Endocarditis - causes, symptoms and treatments [www.bhf.org.uk](http://www.bhf.org.uk)

The importance of good oral hygiene for cardiac children cannot be stressed enough – and all healthcare professionals caring for these children should aim to promote good oral hygiene and 6 monthly dental checks.

The audit highlighted that the current referral system has poor compliance. A summary of the audit findings was shared at a recent governance meeting. Cardiologists and PECs (paediatricians with expertise in cardiology) have agreed to ensure that patients who will need cardiac surgery are referred to a community dentist prior to them being presented for discussion at the JCC (Joint Cardiac Conference). This should hopefully ensure more timely dental referrals and ensure there are no delays in patients being listed for surgery.

 If you have any questions about this audit, or the dental/surgical pathway, or would like any information regarding reducing the risks of endocarditis please contact the cardiac nurses on 0117 342 8286.



**NHS**  
University Hospitals  
Bristol and Weston  
NHS Foundation Trust  
Patient information service  
Bristol Royal Hospital for Children

**Healthy teeth make a safer heart**



## What have teeth got to do with the heart?

This leaflet tells patients about the importance of healthy teeth when undergoing congenital cardiac interventional procedures and why it is especially important for people with a congenital heart condition to maintain good dental health

<http://foi.avon.nhs.uk/download.aspx?did=20296>



## Tom's story



My name is Tom Large, and I have known about my congenital heart disease my whole life. I was born with a bicuspid aortic valve. I've now had valve surgery twice with the surgery carried out by Mr Andrew Parry and the team at the Bristol Heart Institute.

Even though I had valve replacement surgery aged 21 and I never missed an appointment knowing another operation would eventually come, it was still hard to take in when Dr Szanthy explained it was time again. I felt healthy for a start, but the charts clearly showed my aortic valve – a replacement tissue one – was getting stenotic (sticky). Aged 33, it was clear I needed heart surgery again.

It was only a matter of a few weeks before my symptoms became quite severe, with chronic fatigue and a dull ache in my chest. I was very anxious but the cardiac nurse specialists were exceptionally good at listening to my concerns, passing information to the doctors about the changes in my condition and connecting me up with the team's psychologist to help keep me mentally strong.

Then one night I woke up and did not feel right and I instinctively knew I needed to go to hospital. My local A&E decided to admit me and, at first, I believed it would not be long before I was going home again, but the hospital contacted the Bristol Heart Institute and transferred me. It was clear from the ECGs, echocardiograms, and the CT scan I needed surgery urgently.

I found choosing what valve I would have incredibly hard despite it being easy on the previous occasion. I had thought about it in advance but if I am honest with myself not in enough detail. The more I listened to the evidence about the risks and rewards of both surgeries I became convinced a mechanical valve would give me the best quality of life going forward.

I am completely sure it was the right choice and it was made easier by the brilliant nurses and doctors, who were patient with all my questions. My advice to others is to listen carefully to the medics, ask all the questions you have, be self-aware when considering your options and then decide and be confident in your choice.

There is no escaping how very nervous I was going to theatre, but reflecting now on my most vivid memory it is waking up in intensive care, speaking to my partner and hearing everything had gone well.

As this was my second surgery knowing what to expect was also beginning to have some benefits too. For example, I was eager to spend as much time out of bed as I could to help my lungs and chest get better, and I made a point of always asking the doctors and nurses what I could do to help myself improve. Bringing this positive attitude to my recovery made a big difference, and I have no doubt I got home earlier because of it.

Once home, recovery can be a long and slow road. The trick I found when I had a down day was to remember how far I had come compared to one or two weeks earlier. A good support network of friends and family was crucial for me. Give yourself and your loved ones some goals and targets to look forward to, because it is just as hard for them as it is for you.

I have also felt strongly that I wanted to give something back. After my first surgery, I ran the London Marathon for a heart charity.

This time I am using some of my skills from my job in government communications to support the South Wales and South West Congenital Heart Disease Network.



Tom shared his experience of cardiac surgery and care at the CHD Network Board in October 2022 – this meeting is attended by staff and patient representatives from across the South Wales and the South West region.



## 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](mailto: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](mailto:achdnurse.cav@wales.nhs.uk)

**CNS Telephone:** 029 2184 4580

**Appointments & non-clinical queries:** 029 2184 3892 or via [achd.cav@wales.nhs.uk](mailto: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](mailto: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](mailto:PaediatricCardiac.Cns@wales.nhs.uk)

**CNS telephone:**

Cardiff & Vale 029 2184 5184

Bridgend, Merthyr, Rhondda 029 2184 7021

Gwent 029 2184 5524

Swansea and West 029 2184 4753

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

Fetal care 029 2184 1746

**Appointments and non-clinical queries:** 029 2184 4749

## Want to know more?

The network website is for patients, families and clinicians.

We have information on:

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

Scan this code with your phone to visit the network website



**Thank you for reading!**

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

**spring 2023**, please contact

[Rachel.Burrows2@uhbw.nhs.uk](mailto: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](mailto:Rachel.Burrows2@uhbw.nhs.uk) requesting our newsletter