South Wales and South West
Congenital Heart
Disease Network

Spring 2022
Issue 11

Newsletter

Inside this edition

Clinical Director’s Introduction

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

There was hope that COVID-19 would be very much behind us at this point in time, however there is yet another small surge affecting all ages and providing challenges to staffing hospitals in general.

Some projects, as you will read, are being reinvigorated now that we see some light at the end of the tunnel. For example, improving the transfer from the paediatric to adult arenas is a pivotal point in any patients journey. We also launched a virtual tour of the Bristol Heart Institute to help teenagers and parents alike through what can be a daunting process.

Where COVID-19 has curtailed some areas of our work, others have prospered; the clinical psychology, medical and fetal cardiology teams have all offered successful online education opportunities, as you will see within, and our nursing teams continue to work tirelessly and innovatively to meet the needs of patients and families.

Charities continue to support our CHD patients throughout the region, and I am particularly pleased to read about the “I can” project by Heart Heroes. It is so important to look at the positives for our patient community.

I am also delighted that we can announce the result of our inaugural staff photo competition, and allow our staff around the region to share some of their spectacular local landscapes.

Finally, by the time you read this we will have said goodbye to our Network Manager, John Mills, who has reached the end of his seconded time with us. We thank John for his contributions to our network during the last year, wish him luck in his next challenge and look forward to welcoming his replacement in our next issue.

Enjoy reading and hopefully you can also contribute to future editions.

Dr Andy Tometzki
Network Clinical Director

Front cover heart photo – courtesy of Lisa Patten,
Cardiac Clinical Nurse Specialist

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 that work together.

Network Team Key Contacts

Clinical Director: Dr Andrew Tometzki
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Lead Nurse: Sheena Vernon
Sheena.Vernon@uhbw.nhs.uk

Lead Nurse: Jess Hughes
Jessica.Hughes@uhbw.nhs.uk

Network Manager: John Mills

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

Lead Psychologist: Ness Garratt
Vanessa.Garratt@uhbw.nhs.uk

Transition in the network

By Jess Hughes, CHD Network Lead Nurse

What is transition and why is it important?

Transition is the process of preparing patients for adulthood and adult-oriented care. It involves a change in the approach to medical and psychosocial care by the patient and clinician as well as the knowledge and skills to adapt to these changes.

The process often requires a shift from paediatric family-centred care to adult patient-centred care, and patients learning new strategies for managing health and coping with complex medical decision making. The process also involves educational and career focused advice to appropriately prepare for a productive adulthood.

Most children will accomplish a transition to adulthood and achieve independence at some point in their lives. For children with chronic medical conditions, this is equally, if not more, important because poor transitions and gaps in care have been associated with increased morbidity, emotional stress and poorer long term outcomes, and patients being lost to follow up.

What are we doing to improve this process?

The transition pilot project started in 2019 but was paused due to a lack of CNS resource and then the impact of Covid-19.

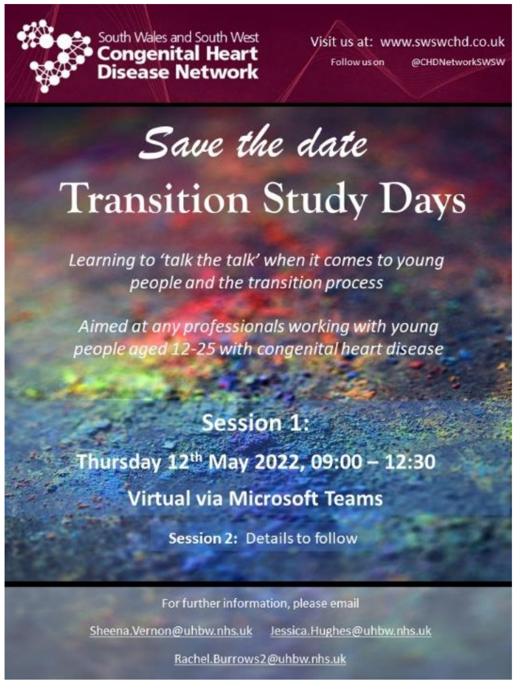
We are very excited to re-invigorate this project and will be writing to the interested centres to assess suitability to take part.

The project aims to set up 2-3 pilot transition clinics for young people around the South West of England and would involve a member of the Bristol paediatric CNS team travelling with the visiting consultant to deliver these clinics alongside the local team.

Education to support this

Transition conversations can be complex and challenging for both clinicians and patients. To support these processes the network is holding two study days aimed at empowering clinical teams involved in the transition process.

The first study day is being held virtually on 12th May 2022!



South Wales and South West
Congenital Heart
Disease Network

Visit us at: www.swswchd.co.uk
Follow us on @CHDNetworkSWSW

Save the date

Transition Study Days

Learning to 'talk the talk' when it comes to young people and the transition process

Aimed at any professionals working with young people aged 12-25 with congenital heart disease

Session 1:
Thursday 12th May 2022, 09:00 – 12:30
Virtual via Microsoft Teams

Session 2: Details to follow

For further information, please email
Sheena.Vernon@uhbw.nhs.uk Jessica.Hughes@uhbw.nhs.uk
Rachel.Burrows2@uhbw.nhs.uk

Visit the CHD network website via the following link or QR code to access a toolkit which will help explain what will happen during transition from paediatric to adult services:

www.swswchd.co.uk/en/page/toolkits-for-teenagers

Spotlight on the Adult Cardiac Clinical Nurse Specialist Teams

Who are we?

The network has two adult cardiac nurse specialist (CNS) teams, one based at the Bristol Heart Institute (BHI), supporting adult CHD patients in the South West peninsula and one based at Cardiff and Vale Hospital, supporting adult CHD patients in South Wales. Patients attending outreach clinics will also receive support from the clinical nurse specialist teams.

Both teams are comprised of experienced nurses who work as part of the wider multidisciplinary team to provide ongoing information, advice, and support to adults with a congenital heart condition, and their relatives/carers. Both teams work closely together to ensure seamless care for Welsh patients who come to Bristol for surgery and catheter procedures, these patients may continue to receive ongoing follow up from their local level 2 centre (Cardiff) or level 3 centre (district general hospital).

When will you meet us?

The CNS teams provide a point of contact (advice telephone line and email for clinical queries) for Adult CHD patients, their families/carers, and allied health professionals, and offer advice and information as follows:

- Advocate for all CHD patients
- Surgical/cardiology issues and general clinical queries
- Transition (transferring from the children's hospital to adult services)
- Support for patients with a learning disability
- Psychological support (ACHD psychologist also available)
- Lifestyle advice
- Living with a lifelong condition
- Financial / employment and education issues
- Contraception and pregnancy
- End of life support

When you are staying in hospital - The CNS teams support patients when they are admitted into hospital and throughout their stay in the level 2 centre (Cardiff) and the level 1 centre (Bristol).

At your outpatient clinic appointments - these include:

- Nurse led pre assessment clinics (for cardiology/ cardiac surgery procedures)
- Nurse led follow up clinic (for clinical and lifestyle support)
- Consultant clinics (new and follow up patients)
- Young persons' clinic
- Cardiac obstetric clinic

The CNS team also offer an ongoing education programme for nursing staff who are involved in the care of our ACHD patients, work collaboratively to promote awareness of CHD, inform standards of care and enhance patient experience across our network.

How to contact the Bristol Heart Institute ACHD Clinical Nurse Specialist team

Phone: 0117 342 6599 (Monday to Friday 8am until 5pm)
Email: ubh-tr.achdclinicalnursespecialist@nhs.net

How to contact the Cardiff ACHD Clinical Nurse Specialist team

Phone: 029 2184 4580
Email: achdnurse.cav@wales.nhs.uk

Both teams have the same ultimate goal to provide an expert, accessible service to all adult CHD patients and their families no matter where they live in the network catchment area.

Here is a photo of Sarah Finch, ACHD Clinical Nurse Specialist in Cardiff, running a CHD awareness session in February 2022

The adult CHD clinical nurse specialist teams work closely with paediatric colleagues to deliver a lifespan service for CHD patients. Both teams are involved with the transition of young patients from paediatric to adult services (see page 3) – find out more on the next page about the virtual tour film the Bristol ACHD clinical nurse specialist team helped create to support patients!

Bristol Heart Institute Virtual Tour Premiered in October 2021!

To support young people during the Covid-19 restrictions and beyond

Young people born with congenital heart disease will transfer to adult services when they are 17 years old, the majority of whom will require lifelong follow-up.

We know that transferring from paediatric to adult services may feel daunting for some of our young patients with CHD, for a number of reasons. To help answer some of their questions, address any concerns and provide support, our network lead nurse Sheena Vernon, and the adult clinical specialist nurse team in Bristol have created a film to give patients and their families from across South Wales and the South West CHD network an idea of what to expect if they need to come to the Bristol Heart Institute for treatment.

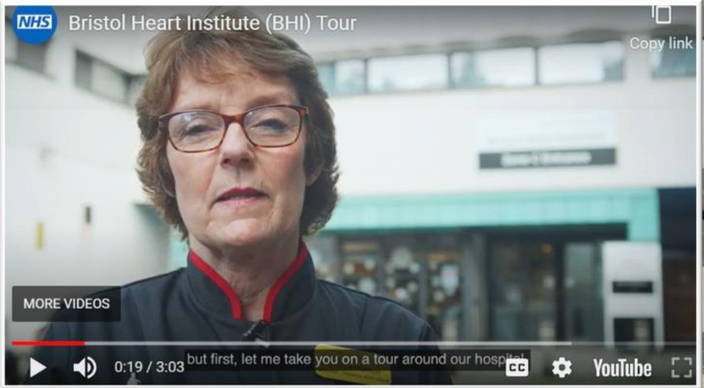
The virtual tour film gives an overview of the Bristol Heart Institute and a commentary to describe the clinical areas, the team, and what it will be like for patients coming to the hospital. This film makes the information widely available to all those young people and families who may be seen in peripheral clinics across the South Wales and south west network, and for whom it may be difficult to travel a long distance to come and visit the Bristol Heart Institute for an in person open evening.

View the film on the network website via the QR code below or this link:

https://www.swswchd.co.uk/en/page/adults

The young people's 'open evenings' at the Bristol Heart Institute were put on hold in 2020 due to the COVID-19 pandemic. The purpose of these evenings is to provide an opportunity for young people and their families who are transferring from the children's services to adult services to come and visit the Bristol Heart Institute. It is an opportunity to meet the medical and nursing teams, ask questions, have a tour around the hospital, to meet the ward staff and see what the outpatient department and the wards look like.

The Bristol paediatric and adult CHD teams were delighted to hold a virtual young people transition evening on 29th March 2022.



Bristol Heart Institute (BHI) Tour

but first, let me take you on a tour around our hosp

Paediatric Quality Improvement Project: QR code posters now available!

With thanks to Abhishek Oswal and Wendy McCay, clinicians at the Bristol Royal Hospital for Children, the QR code project posters are now available and have been published on the network website.

“For professionals working with families of children with congenital heart disease, a commonly-faced challenge is finding appropriate resources to help improve patients understanding of their condition. For this reason, and in view of the COVID-19 pandemic and the increasing drive to reduce reliance on paper resources, we have designed posters based on QR codes which link to British Heart Foundation leaflets.”

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
- Having individual codes on patient clinic letters, particularly when lesions are newly diagnosed.


Understanding your heart:
A series of booklets from the
British Heart Foundation

Bristol Royal Hospital For Children

NHS
University Hospitals
Bristol and Weston
NHS Foundation Trust

“Straight from the heart”
Arrhythmias
Aortic Stenosis
Atrial Septal Defect
Coarctation of the Aorta
Hypoplastic left heart syndrome
Implantable cardioverter defibrillator (ICD)
Long QT syndrome
Pulmonary atresia with intact ventricular septum
Pacemakers
Pulmonary stenosis
My heart operation
Transposition of the great arteries
Transition to adult services
Tricuspid atresia
Ventricular septal defect

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 as a pop up!
Try it on the code to the right to go to SWSWCHD network page of the hospitals in the region
Please provide feedback on this poster by scanning the code on the left

The posters can be downloaded from the network website:

https://www.swswchd.co.uk/en/page/children

The British Heart Foundation (BHF) is one of the UK’s best known heart charities and the research it has funded has contributed a huge amount to progress in the care of patients with congenital heart disease.

Professor Massimo Caputo, a BHF top Professor based at the CHD network’s level 1 centre and the University of Bristol, is leading exciting research in the field. You can find out more on his and his team’s work on the BHF website.

Tales from the Ultrasound Clinic

Tales from the Ultrasound Clinic is an artist-led participative exploration of the imaged lives of pregnant women with heart disease. Women whose heart stories are unique and not often heard.

Working with patients and clinicians, artist Sofie Layton has been attending the specialist antenatal cardiac clinic at St Michaels Hospital over the past 5 months. During this time, she has been meeting mothers and partners, witnessing the mesmerising movements of the hearts and its complexities through the echocardiogram process, and sitting in on consultations with the cardiologist and obstetrician with the mothers and partners permissions.

Additionally Sofie has been running online workshops exploring creative writing exercises exploring different narratives around the heart. One mother, when asked what animal her heart would be, responded that it would be a cheetah as its runs so quickly but now since she is pregnant it has calmed down. Another mother described her heart as an opera that had caused an on-going drama throughout her life.

These fragments and ideas are in the process of being woven together into a blue amniotic world which will become the foundation for an immersive artwork, in turn acting as a reflection around medical imaging and pregnancy in today’s medical landscape. Sofie is working with sound artist Jules Maxwell on a soundscape that brings these conversations around the mother and her baby’s heart together through poetry and music.

This project builds on an extensive exploration into narratives of the heart that first began in 2015 at Great Ormond Street Hospital where Sofie was an artist in residence as part of a Wellcome Trust Arts award. This grew into a much bigger collaboration with bioengineer Dr Giovanni Biglino and Professor Jo Wray, and led to the creation of a committed interdisciplinary team and the conception of The Heart of the Matter www.insidetheheart.org, a national project culminating in a touring exhibition in 2018.

Tales from the Ultrasound Clinic is the first new work that Sofie and the team are developing within a real hospital setting and not a virtual space, since the Covid-19 pandemic, although pregnancy and its complexities in relation to heart disease is a challenging place to begin as there are two patients involved in each encounter.

The work is rich and has been supported by all the staff at the cardiac antenatal unit led by consultant cardiologist Dr Stephanie Curtis – who described her own heart as a lion!

Pause for thought: If you were to describe your heart as an animal, what animal would your heart be and why?

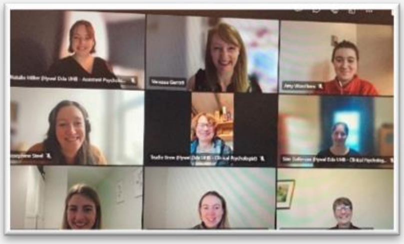
Education and training

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 Psychology Network Day – held 15 February

The third annual regional network psychology day, gathered eleven psychologists, trainee psychologists and therapists from the Southwest and South Wales who may see cardiac patients in a range of places (adult and child community mental health teams, health psychology teams and specialist cardiac teams).

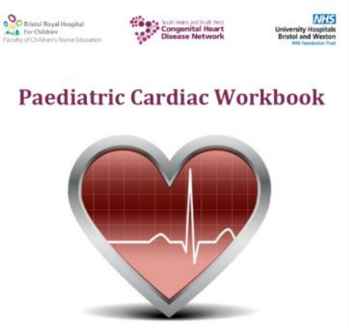
The aim of the day was to continue to connect health professionals together from across the region, share experiences, enhance skills on managing common issues and how to link into specialist psychological cardiac services when needed



Published: Paediatric Cardiac Work Book

The CHD Network are proud to have published the Paediatric Cardiac Workbook, which has been produced at the request of the network by Bristol Royal Hospital for Children, led by Carla Sims (Senior Staff Nurse and Clinical Skills Facilitator for Dolphin Ward – specialising in cardiac care) with input from the network core team, Alison Wood (see page 9) and several others.

The work book is designed to offer an overview of paediatric cardiology, covering basic anatomy and physiology of the heart as well as developing knowledge of common congenital cardiac conditions. It is aimed at all nurses within the South West and South Wales CHD Network who care for children with a congenital heart condition and who wish to enhance their knowledge. The content may be new knowledge for some and revision for others.



Bristol Royal Hospital for Children

South Wales and South West Congenital Heart Disease Network

NHS University Hospitals Bristol and Weston

Paediatric Cardiac Workbook

The suggestion is that the work book is completed within six months to ensure maximum benefit, and this could be considered with managers as an appraisal objective.

The work book can be found on the nurse education page of the network website: https://www.swswchd.co.uk/en/page/chd-achd-nurses-link-nurses (under the training and education section).

Thank you to all those involved

2021 Adult CHD annual study day

This annual regional event was held virtually on 19 October, led by Sheena Vernon, lead nurse, and the Bristol ACHD clinical nurse specialists. Being online made it very accessible, with over 130 staff attending from across the region and beyond. The topics included pulmonary hypertension, surgery for cyanotic patients, the role of psychology and advanced care discussions for patients with complex conditions. Plans are already underway for the 2022 event!

2022 South West Paediatric Cardiology Education Forum (winter)

This regional event was chaired by Dr Nigel Osborne and held virtually on 21 January, with engaging presentations from consultants in Bristol. Topics included: assessment of the pericardial effusions; transcatheter PDA closure in preterm infants; technological advancements in paediatric electrophysiology.

Up next… the Welsh Paediatric Cardiovascular Education Forum is being held on 29 April 2022.

Cardiac Physiologist Forum

The quarterly virtual forum for cardiac physiologists from across South Wales and the South West, continues. This is a fantastic opportunity to share good practice and knowledge, work collaboratively, develop project ideas and discuss challenges. It was great to have a spotlight presentation at the March 2022 Network Board on emerging regional physiology initiatives. The next virtual meet is planned for 7 June 2022.

Details of training and education events can be found on the network website. A number of specialist training events, including fetal cardiology, national and international meetings, are also publicised there.

What's coming up regionally?

- WPCN (PEC) education forum, 29 April 2022
- Transition study event, 12 May 2022 (see page 3)
- Level 1 & 2 Clinical Nurse Specialist Day, 7 June 2022
- Physiologist virtual meet, 7 June 2022
- ACHD study day, 18 October 2022

FETAL CARDIOLOGY UPDATE

By Angie Hobbs, Fetal cardiac and midwife sonographer, Bristol

Bristol Royal Hospital for Children successfully hosted our first fetal cardiology study day on Friday 28 January 2022, led by Dr Patricia Caldas, paediatric and fetal cardiologist, and sponsored by Canon Medical systems. This event was originally planned for March 2020 but had to be postponed due to the COVID-19 pandemic.

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

77 delegates attended the hybrid event joining in person and virtually, including fetal medicine specialists, sonographers, trainees and paediatricians from across the network and beyond. The day was very well received with comments such as

"Good overview & practical approach to fetal cardiology"

"The course was jam packed full of super useful information"

"The whole content was great."

The success of the cardiac network and its positive impact was the inspiration for the creation of these courses and the fetal cardiology team continues to provide support and education for the region.

Next steps! Already planned are 'In-house study days with hands on sessions for sonographers in Cornwall and Taunton.

We are also very excited to announce the next study day on 7 October 2022. Following feedback, this day is aimed specifically for sonographers performing the 18-20+6 weeks screening scan (20 week anomaly scan). The aim of the course is to improve skills and confidence in detecting congenital heart defects. More to follow soon!

Fetal Cardiology webinar series

Whilst the study day was on hold due to the COVID-19 pandemic, the fetal cardiology team embraced new ways of working with launching a fetal cardiology webinar series in 2020-21.

The webinar series is still available on the South Wales and South West CHD Network NHS Future Platform! Network healthcare professionals can register for this by emailing: SWalesSWCHD-manager@future.nhs.uk

FutureNHS

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
- New Psychology platform
- ACHD study day resources
- Physiology platform *(currently under development)*

If you think a professionals education page would be useful for your team/staff group please do let us know.

Watch this space!
A new 'Events' page on the network website is coming soon

Meet Alison Wood

Paediatric Cardiac Nurse Educator

Alison is a paediatric cardiac nurse educator working with the Faculty of Children's Nurse Education at Bristol Royal Hospital for Children. She is relatively new to this post, having previously worked for many years on the cardiac ward

"Working within the cardiac speciality, I have seen many changes to the treatments that we are able to provide and the benefits these bring to patients. It is an exciting new challenge to share my knowledge and experience within my teaching and I enjoy seeing students link up theory and practice, knowing that it will help them to be better nurses.

Children's cardiac nursing: foundation level course (open to staff across the South Wales and the South West CHD Network)

Target audience: During my role so far, I have been focussed on delivering foundation level courses, teaching children's cardiac care to nurses who are new to the cardiac ward and Paediatric Intensive Care Unit (PICU), and to those nurses with more extensive experience regionally, who care for cardiac children within their workload, but not as a speciality.

Overview: This course teaches the 'normal' heart, as a basis from which to learn about some of the more common congenital heart defects. The aims are to provide knowledge of patient pathways, from the point of diagnosis, looking at medical/surgical care, through to an awareness of prognosis in adult life. It also encompasses the care provided by the multi-disciplinary team.

How to apply: FacultyOfChildrensNurseEducation@UHBW.nhs.uk

My educator role is so different to direct, ward-based patient care, it has felt like a career change at times. Identifying the key concepts that are important for nurses to know and finding novel ways of disseminating that learning, whether that is though the students using play-doh to model heart defects, or them making videos of their practical skills.

Delivering education: new ways of working

The COVID-19 pandemic has affected the way we have delivered education. Previously the course was entirely classroom based, but due to the pandemic this shifted to social distancing in a large lecture theatre, to being delivered online. The courses operated through a video-conferencing platform to deliver 'live' lectures, alongside an online learning website to provide reading material / videos to the students with quizzes to check their understanding. This was a new but positive experience for the course attendees as well as me. Going forward we are returning to face-to-face education, but it is likely that an element of distance learning will remain.

Children's cardiac nursing 2: enhanced level course

Further developments to my role include running a new enhanced level cardiac nursing course, planned for May 2022, which at present is solely open to staff at Bristol Royal Hospital for Children, however this may be offered to a wider audience in the future. This course will delve deeper into CHD, to give nurses a more extensive understanding of the full range of cardiac anomalies including the rarer defects."

"I hope to work more closely with the South Wales and South West CHD network to review the educational needs of nurses across the region, and to collaborate with other cardiac surgical centres to benchmark the education that I am providing."

National projects

Alison Wood has been working with Jess Hughes, network lead nurse, as part of the national project team to create CHD learning modules on the e-Learning for Health platform. Find out more on the next page!

Health Education England education modules

By Jess Hughes, CHD Network Lead Nurse

How did they start?

In 2021, Linda Griffiths, the lead nurse for the North Wales, North West and Isle of Man CHD Network undertook a survey of nurses across the country to assess their educational needs when it came to patients with CHD.

The result was that more education was needed and the idea for this project began. A team of lead nurses, clinicians and educators from around the UK assembled and began to work on three e-learning for health modules, funded by Health Education England. These modules are entitled:

- An introduction to Congenital Heart disease

  An overview of the prevalence and classification of congenital heart disease and the advances in care that have resulted in increased numbers of patients surviving with complex disease.

- The neonate with duct dependent congenital heart disease

  An overview of fetal cardiology, antenatal diagnosis, common duct-dependant lesions and the delivery of continuous intravenous prostaglandin in these instances. To consider the clinical signs and symptoms of CHD in infancy.

- The adult with congenital heart disease

  Aims to equip learners with basic but essential knowledge of morbidity and mortality in adult patients with congenital heart disease. Includes an appreciation of how Adult Congenital Heart Disease patients present acutely unwell, initial management of these patients, and when and where to seek expert advice.

Who are they for?

The educational market was widened from nurses to all professionals caring for children and adults with CHD who are not experts in the field. This would include: general practitioners, midwives, health visitors, practice nurses, neonatal consultants and nurses, and any other colleagues from the multidisciplinary team who would like to learn more about this patient group.

All NHS clinical staff who are not specialists in this subject but may need to care for patients with congenital heart disease in their current role. Although congenital heart disease is a specialised subject, these patients will interact with all other areas of the NHS throughout their lifetime. It is therefore important that all NHS staff are aware of the implications of congenital heart disease, know when to ask for expert advice and know how to do that.

NHS
Health Education England

When will they be available?

The modules are currently in the graphic design phase and will be available soon.

Details to follow on how to access the modules when they have been released!

There will be a communications press release that will go out to all networks, acute and primary care providers.

This exciting project has involved a huge amount of collaborative working across networks and will be the start of many more modules on the subject of CHD

e-LfH
e-Learning for Healthcare

News from the CHD psychology team

By Vanessa Garratt, Network Lead Consultant Clinical Psychologist

I'm delighted to be part of such a wonderful skilled cardiac psychology team. Our team have worked hard to support families and put together resources and webinars during the pandemic, which are described below for you to access.

We have some changes coming up as we congratulate Amy Woodham (paediatric cardiology) in looking forward to having a baby in the summer and Hannah Mustard (ACHD team) and Josie Steel (paediatric cardiology) in developing their skills in new roles in our wider Bristol team.

We are actively recruiting to our roles and look forward to introducing our new psychologists to you. We will be focusing on our inpatients during the gap in service and will still have our resources and new preparation packs for surgery that we are developing for you to access.

In exciting news in Wales we welcome the return of Llinos Griffiths, after her maternity leave who provides psychological support to paediatric patients and Anna Mcculloch, who is one of two psychologists supporting adults with congenital heart conditions which is a new service. This is with thanks to a successful national business case that released funds to enhance the ACHD service in Wales.

We are working hard to connect our network psychologists across the region so your local teams have access to all of our resources and we are working together to support you in your cardiac journey.

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.swswchd.co.uk/en/page/getting-support

Getting the support you need

We are looking forward to sharing with you the recorded paediatric webinars that are due to be released soon – these cover:

- 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

Please let us know what topics you would like us to develop webinars for next.

On a personal note

By Hannah Mustard, Clinical Psychologist

It is a year since I was appointed to the Adult Congenital Heart Disease (ACHD) service at the Bristol Heart Institute and I am sad to say that I am leaving the post for a permanent contract elsewhere in the Trust.

It has been a pleasure to work as part of the ACHD service while Michelle O'Keeffe, Clinical Psychologist, is on secondment and I have really enjoyed connecting with the wider SWSWCHD Network whenever possible. I will be leaving the service in March 2022 and there will be a period of time without an ACHD psychologist while the recruitment process takes place.

It has been a privilege to work in ACHD and in particular I have found the emphasis on the inclusion of patient representatives in the work of the Network so important and have really appreciated what this represents in terms of patent-focused values in healthcare.

Whenever I have connected with people via the Network, whether for a project or arranging the Network Days, I have been struck by the enthusiasm with which people approach this work, even during the very difficult times we all faced last year.

Thank you to everyone I have connected with over the time I have been in post. I sincerely wish you all a very happy 2022 and all the best for the future.

Welcome

Dr Anna Mcculloch

Consultant Clinical Psychologist

I am delighted to be joining the CHD network as consultant clinical psychologist in specialised cardiac services based at University Hospital Wales in Cardiff and am looking forward to working with everyone.

Tell us a little about your background

I gained my doctorate in Bristol, a course which specialised in working with people with physical health conditions and have worked in different medical settings since qualifying in 2010.

I have a post graduate diploma in cognitive behavioural therapy and often draw from acceptance and commitment therapy and compassion focused therapy.

What are your interests/passions?

- Supporting people with chronic or life limiting conditions to live a meaningful and enjoyable life.
- Empowering people with health conditions to play a central role in their healthcare
- Supporting healthcare professionals in providing compassionate care
- Ensuring that people have excellent end of life care

What do you enjoy doing outside of work?

When I am not working as an unpaid taxi driver for my three children, I like to take brief sea swims and connect with others. I find taking time to laugh and have fun is the best way of recharging my batteries.

During Anna's first week in post she delivered a fantastic presentation at the 2022 network psychology day on embedding psychological care.

Anna has also joined the CHD network board that meets on a quarterly basis.

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

Welcome to the network Dr Davide Marini, consultant in paediatric cardiology in Bristol, who joined the team in January 2022. Welcome also to Dr Lalit Bhalla, the new clinical director for Adult CHD services in the Aneurin Bevan Health Board.

Welcome to Emma Benger, new paediatric clinical nurse specialist in Cardiff, and to Amethyst Loughlin, administrator supporting the clinical nurse specialist team at Bristol Royal Hospital for Children.

We would also like to welcome Marian Thomas, cardiac physiologist in Swansea who is currently training part-time in paediatric echo services.

At the Royal Cornwall Hospital, we welcome Nigel Oakes, new services manager covering adult CHD, and Catherine Rule, new service manager for paediatric CHD services.

We bid farewell to John Mills, network manager, who is leaving in April to take on a promotion in the NHS – congratulations John!

We also said farewell to Guido Pieles, consultant cardiologist, and to Ines Batista Gomes, consultant cardiologist, who both worked at the Bristol Royal Hospital for Children and supported the regional peripheral clinics.

At University Hospitals Bristol and Weston, we said goodbye to Josie Sweetland, specialist psychologist in paediatrics, and to Hannah Mustard, specialist psychologist in adult CHD.

Introducing Gui Rego
Clinical Physiologist in Adult CHD

Current role and experience

Gui qualified as a clinical physiologist in Portugal back in 2011 and quickly realised his passion for the echocardiography field. After an international experience in Portugal, Finland, France and the Azores, he moved to Bristol in 2015, initially worked in the Bristol Royal Hospital for Children and then took a senior echocardiographer position at the Bristol Heart Institute.

Echocardiographers determine if a person has heart disease by looking at the walls and muscle motion, seeing how the valves are working, or visualising the overall structure.

Pursuing constant professional development, Gui obtained the British Society of Echocardiography accreditation in adult echocardiography followed by the European Association of Cardiovascular Imaging congenital heart disease echocardiography certification.

More recently, after obtaining his Scientist Training Programme equivalence (a masters level in clinical science) from the Academy for Healthcare Science, he applied to a five-year Higher Specialist Scientist Training workplace-based programme that provides opportunities for clinical scientists to study towards a doctorate level. Gui is also passionate about education in this field, leading to him becoming an assessor for the British Society of Echocardiography since 2019.

Involvement with CHD

Gui had his first exposure to the world of congenital heart disease whilst working in Paris. After his European accreditation in CHD echocardiography, he became a dedicated echocardiographer in Bristol Heart Institute in this speciality.

He is often seen in the department during the adult congenital heart disease clinics or the Inherited Cardiovascular Conditions service.
Gui is part of the South Wales and South West Congenital Heart Disease Network and the National Congenital Heart Disease Steering Group.

With his doctorate now underway, Gui aims to develop research in the field of complex congenital heart disease. His main objective is to develop more in-depth understanding of the assessment of the heart function using existing evidence based tools as well as novel techniques, and adapt this to the ACHD population. This could potentially allow better clinical management, and ultimately a better quality of life for these patients.

Interests outside of work

Gui is also a keen musician, taking up the piano as a child and later developing an interest in singing. Nowadays, he sings with the Costanzi Consort, Bristol Bach Choir and Nova Choir as a tenor.

He loves travelling, trekking, spending time in nature, running, going out to the cinema or spending time with his friends and family. He hates spiders and loves coffee – a lot!

What is an echocardiogram?

An echocardiogram, also known as an echo, is a non-invasive test which uses sound waves to build up a detailed picture of your heart. It is similar to ultrasound scanning used in pregnancy.

An echo looks at the structures of your heart, and gives information on how well your heart is pumping. It is used routinely to diagnose and assess congenital heart conditions.

Source: British Heart Foundation website

Did you know...

The CHD network has a quarterly virtual meeting with cardiac healthcare scientists, physiologists and sonographers from across the region. There are lots of exciting initiatives emerging from this group.

Gui is involved with a project group led by Carys Williams (Swansea) and Owen Burgess (Bristol) that launched in January 2022 to develop a physiologist education and resources site on the network NHS Future Platform!

Network update

By John Mills, Congenital Heart Disease Network Manager, South Wales and South West

The SWSW CHD Network has had another busy six months! Since the last issue of our newsletter we have supported all level 3 CHD services in South Wales to complete a self-assessment against NHS England CHD standards, and were impressed by the high level of engagement in this process. The recommendations from this process should help to promote investment and improve CHD services for all Welsh patients.

We have continued our wide programme of events and education for staff groups, including sessions for consultants, nurses, psychologists, and cardiac physiologists, which have been consistently well-attended and well-reviewed. We have made further steps to support the development of nursing staff with the recent launch of our CHD nurse competencies and paediatric cardiac workbook; and have been developing online education platforms for medical, psychology and physiology staff, which will no doubt be a fantastic resource as content grows.

The network team have continued to work closely with our excellent patient and parent representatives to ensure that the patient voice is central to our activities, and they are already making plans to welcome more individuals into this group and improve our engagement further in the coming year. If you think you might be interested – please do get in touch!

Huge thanks go to all those who have contributed to these successes so far. We have another ambitious work programme agreed for 2022/23, so expect much more to come as the year progresses!

Network Board meeting (above)

Our Network Board meetings have been virtual since 2020. At the network board in March 2022, there was a spotlight on physiology with an update from cardiac physiologists across the network. We opened with a patient story about the experience of transition from paediatric to adult services with additional learning needs.

National context

Our CHD Network for the South Wales and South West region is one of several similar CHD networks across England and Wales (with separate CHD networks for Scotland and the island of Ireland).

Some problems are greater than just our region so we come together with other CHD networks to work on these. Since the COVID-19 pandemic, we have facilitated regular national 'network of CHD networks' conference calls, primarily to discuss COVID-related impact, response and recovery. These calls continue on a monthly basis.

We are also working together strategically to find ways to grow and develop our adult CHD workforce in line with the growth we have seen in demand for ACHD services.

Network managers meet several times a year to share updates, discuss ideas and learn from one another about how best to engage, support and serve our CHD patients.

Network dates for your diary!

Key network meetings:

12 July 2022: Network Board &
Network Clinical Governance Group

11 October 2022: Network Board

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

New Staff Photographic Competition:

'February scenes across the network'

Throughout February 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 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.

Winner

We are delighted to announce that Nigel Osborne, Paediatrician with Expertise in Cardiology at the Royal Devon and Exeter NHS Foundation Trust is the winner with his creative photo of a 'mossy tree in Fernworthy Woods, Dartmoor.'

Runners Up

"A heart shaped rock discovered at one of our local beaches"

Nina Worrin,
Cardiac Nurse,
Royal Cornwall Hospital

"Commute to work. 128-yard viaduct, part of the West Cornwall Railway line operated between 1903-1963"

Georgina Ooues,
ACHD Consultant Cardiologist
Royal Cornwall Hospital

"Holywell Bay, Cornwall"

Katy Huxstep,
Paediatrician with Expertise in Cardiology
Royal Cornwall Hospital

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

Supporting adult patients with additional needs when preparing for a procedure

By Sheena Vernon, Network Lead Nurse

Approximately 17% of congenital cardiac conditions occur in association with a recognised syndrome and this may also result in the patient having additional needs and varying degrees of a learning disability. Some syndromes can be associated with a specific cardiac condition or collection of cardiac conditions. Common syndromes include Downs syndrome, Di George Syndrome and Williams syndrome.

Supporting patients with additional needs when preparing for a cardiac investigation, a cardiac procedure or cardiac surgery requires several steps to ensure the preparation is as thorough as possible for the patient, the family and clinical team.

Capacity Assessment

In explaining the procedure to the patient you need to consider the patient's level of understanding. This may involve verbal explanation, pictures, drawings, using websites or animated diagrams.

Before the patient can sign their own consent, the team need to be clear that the patients have understanding. The patient may be able to repeat back information, be able to point to a part of a diagram or explain their understanding using pictures on a website. If the patient's understanding is difficult to assess, a Capacity Assessment will take place.

The Mental Capacity Act (MCA) assessment is done in stages and four questions need to be answered:

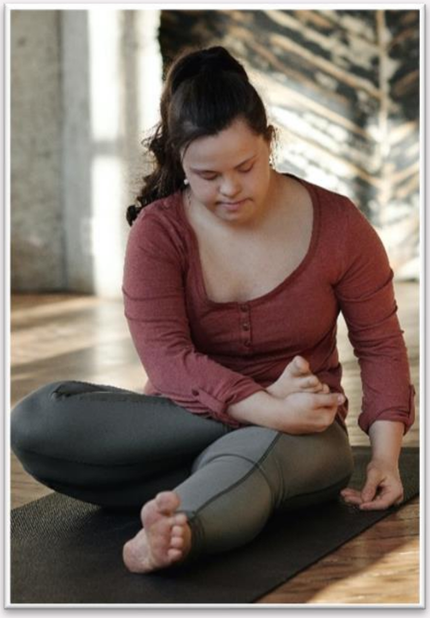
☐ Can the patient understand the relevant information to make a decision?

☐ Can the patient retain the information provided?

☐ Does the patient have the ability to weigh that information as part of the decision-making process?

☐ Does the patient have the ability to communicate their decision?

If the answer to any of these questions is NO, then a best interest meeting will be arranged.



The Mental Capacity Act Assessment of capacity is set out in the Mental Capacity Act (MCA) 2005 and its accompanying Code of Practice.

It provides a framework for caring for or treating people 16-years old or over in England and Wales who lack the ability to make decisions for themselves.

The Mental Capacity Act states that a person lacks capacity if they are unable to make a specific decision, at a specific time, because of an impairment of, or disturbance, in the functioning of mind or brain.

Mental Capacity Act 2005

Code of Practice

Best interest meeting

In the event of the patient being felt to lack capacity, if they are unable to describe the principles of the procedure, a multidisciplinary best Interest meeting will be set up by the adult congenital heart disease clinical nurse specialist team, to support making this specific decision.

Those invited to attend the best interest meeting will include the patient, the family and any carers, and possibly a member of the learning disability team, the patient's consultant and the doctor who will undertake the procedure. If the patient does not have family, then an independent mental capacity advocate (IMCA) will act on the patient's behalf.

If it is felt by all those in the meeting that it is in the best interests of the patient to go ahead with the procedure, a consent form number 4 will be completed and signed by the clinicians.

Preparing for admission

Communication with the wider team will ensure reasonable adjustments are made to support the patient's admission. The patient may bring a patient passport to tell the clinical teams something about their life outside hospital.

If there is a side room available, the patient will be offered it and family or carers are able to stay if needed. Support will also be available from the adult CHD team, and from the adult CHD youth worker if the patient is a young adult.

Bristol Royal Hospital For Children

University Hospitals Bristol NHS
NHS Foundation Trust

Hello, my name is

I like to be called

and I can respond to it. Please use my name when you speak to me.

Who are you?
#hello my name is...

Insert photo of your child here
See instructions on the main webpage or in our leaflet

My Hospital Passport

PREFERABLE INFORMATION
Information about my likes, dislikes and comfort issues

Things I like

Things I don't like

Things that make me feel safe and comfortable

Things that will make my time in hospital better

Going home

When the patient is ready to go home, support will be arranged and they will be seen in clinic a few weeks later. This may be in the Bristol Heart Institute or their local peripheral clinic.

Did you know…
A patient story of a young CHD patient with DiGeorge syndrome was presented at the CHD network board in March 2022

UD Ups and Downs southwest

A Down's Syndrome Support Charity working directly with families, professionals and all those involved with the care and education of children and young people who have Down's Syndrome.

https://www.upsanddowns.net/

dhg down's heart group

Charity offering support and information relating to heart conditions associated with Down's Syndrome.

http://www.dhg.org.uk/

MAX APPEAL
IMPROVING LIVES OF 22Q11 FAMILIES

Supports families affected by DiGoerge syndrome

http://www.maxappeal.org.uk/

I CAN PROJECT

Who are Heart Heroes?

Heart Heroes is a South West-based charity supporting families with children affected by CHD. Through Hubs located in Bristol, Gloucestershire, South Wales, Oxfordshire and Worcestershire the charity, led by founder Kelly Cornish, currently supports 647 families through shared networks, counselling and emotional well-being services, and by providing specialist equipment and experiences for disadvantaged families.

What is the ‘I can’ project?

One of Heart Heroes’ main strands of work involves organising regular inclusive and inspiring CHD-friendly activities for affected children, where the focus is very much on what the children *can* do, rather than what they can’t.

The Gloucestershire Hub’s I CAN project was conceived as a six-month programme in 2021 with the aim of bringing members of the CHD community together (physically and virtually) to mitigate the isolating effects of the pandemic.

Kelly explains: “The focus from the very start of the I CAN project was on celebrating abilities, not disabilities, through organising practical workshops and activities for children with CHD and their siblings in areas they may not have had the opportunity to explore before.

Children with heart conditions often miss out on normal activities in school, whether because teachers are not comfortable in allowing them to take part, or because the children themselves do not have the confidence to take part. Children who undergo surgery are required to isolate for a length of time and the pandemic has impacted the length of isolation even further of course. The I CAN project was specifically designed to help children with CHD reduce their anxiety levels after the pandemic, socialise again and build their confidence in taking part in physical activities safely.”

Launching in September 2021, the programme secured funding for 30 children with CHD to take part in a monthly masterclass run by expert tutors:

I CAN COOK
I CAN EXERCISE
I CAN DRUM
I CAN CREATE
I CAN ACT
I CAN GARDEN

Feedback

The impact for those taking part has been evident in the feedback Heart Heroes has received from parents of the children taking part:

> “I CAN is a one-of-a-kind group. Our daughter often can't be left at activities outside of school due to her complex needs, but we know that Kelly and the team understand those needs, giving us the confidence to leave her.
>
> This allows her the same opportunities as her less complex twin and the chance to develop her confidence and independence through a range of amazing activities. They both love I CAN and to see them connect with others through unique shared experiences is priceless.
>
> I CAN has had a hugely positive impact on our family as a whole - we can't thank Heart Heroes enough!”

Exciting announcement

Heart Heroes has also secured funds to launch the I CAN programme in Bristol, starting with I CAN COOK on 2 April 2022, with 30 families already signed up to take part plus a waiting list of families who will hopefully be able to join an additional programme soon.

Kelly continues: “We work closely with Bristol Royal Hospital for Children to raise awareness of the support Heart Heroes can offer and to reach more families in need, and we are really pleased that the Congenital Heart Disease Network has partnered with us to promote the I CAN project.”

Future plans

Kelly has plans to extend I CAN even further: “Our aim is to fund I CAN programmes within each Heart Heroes Hub area, and to make it available to an older age group as well, as we’ve had lots of parents asking if we can do something to support 11-16 year olds.

Ideas at the moment include I CAN Walk Alpacas, I CAN Exercise in collaboration with #wecanmove and Hartpury University; and an I CAN Protect the Planet environmental campaign. We’d also love to hear from parents if there are any activities they think would be particularly popular with their young teenagers!”

Like to find out more?

If you would like to find out more about Heart Heroes’ work, or would like to join an I CAN programme near you, visit the website at www.heartheroes.co.uk or email Kelly for details on email@heartheroes.co.uk.

Becky’s story

By Becky Nash, Patient Representative

Surgery and mental health – a patient’s perspective

My name is Becky and I have congenital heart disease (CHD). I am also a nurse, a partner and a mum to two young boys aged 5 and 8 years. I have had two open heart surgeries, at 10 years old and 29 years, the latter in 2016 when my eldest son was just 3 years old. I found myself terrified of not surviving the operation and leaving my son without his mum, which I am sure all parents worry about. We are incredibly close, and the idea of him growing up without me was too much to bear.

We made the difficult decision that he wouldn’t visit me in hospital, surrounded by drips and drains, so I didn’t see my son for 10 days, which was hard and painful. The relief and joy when we were reunited was overwhelming, but I am still left with the mental struggles from this experience. Although I am physically well recovered, I suffer with anxiety when separated from my son, the surgical scars affected my body image and self-esteem, and I was diagnosed with post-traumatic stress disorder from the operations.

Support is available to all CHD patients. Permanent make up, gels and creams can successfully help heal or reduce scarring, and I received fantastic support from the adult CHD psychology service. I would encourage other patients who are worried, to access this via their consultant or specialist nurse. I continue to take medication for anxiety and depression and have ongoing support from my GP.

I am so pleased to be feeling myself now and grabbing all life has to offer!
I share this to emphasise that cardiac surgery can significantly affect patients mentally as well as physically. Services have come a long way in terms of available support to ensure people get the support they might need but can still do more.

I would like to end by saying feeling worried, nervous, low or anxious is normal. There is no ‘right’ or ‘wrong’ way to deal with these things. Feel however you need to feel; but know that there is so much help and support available if you need it and you are never alone. You’ve got this!

Thanks for reading!

Supporting patients & families

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

Sometimes it can be hard to know what you need and where to find this.

There are a number of national and local resources on our website that might suit your needs or answer questions that you have.

We also know that different types of support will work for different people. You may prefer to read information and try out strategies at home, see someone locally or access specialist cardiac support via the telephone or in person.

By using the resources on our website you can find out what you need and where you can go to find it. There are a number of types of support available and different services you can access, depending on how much support you need at a given time.

Find out more by going to;
www.swswchd.co.uk/en/page/getting-support

Things that might help: We know there are things that might help to prepare you and/or your child prepare for cardiac surgery. If you would like to find out more please visit our website at:

www.swswchd.co.uk/en/page/getting-support-cardiac-surgery

Heart Families South West

Heart Heroes

heart children gloucestershire

Charity updates

To find about more about the work charities are doing to support patients with CHD and their families, please visit the charities webpage on the network website (https://www.swswchd.co.uk/en/page/charities)

Are you aged 15 - 24 with congenital heart disease (CHD)? We can offer you and your family support. Please get intouch to connect to our congenital heart disease network, or to just have a chat!

YOUTH @ HEART

contactus@youthatheart.co.uk

01452 690 830

"I found having a youth worker helped distract me from the operation and made me laugh"
Young Person Feedback

Youth

- INPATIENT VISITS
- OUTPATIENT APPOINTMENTS
- Preparing for surgery or procedure
- SOMEONE TO TALK TO about education, employment, benefits & finance
- HEALTHY LIFESTYLES
- OUT IN THE COMMUNITY, in college or online, we listen!
- MENTAL HEALTH issues, anxieties or low mood
- Transition and transfer to adult services
- MEET OTHERS IN OUR ONLINE CHD YOUTH COMMUNITY
- Take part in EVENTS and ACTIVITIES

Family

- WHOLE FAMILY IN HOSPITAL SUPPORT
- IN COMMUNITY / home visits for whole families
- INFORMATION / JARGON BUSTING
- MEET OTHERS IN OUR ONLINE COMMUNITY

CONTACT US

Youth @ Heart

Contact Xander
ACHD Youth Worker
07832 668907
xander@youthatheart.co.uk
facebook.com/xander.heart.18

Youth@Heart fund an ACHD Youth Worker, Xander, who's been in post for almost three years. based at Bristol Heart Institute whom the charity work in collaboration with,. Referrals can be made via: xander.patel-cook@uhbw.nhs.uk

#YOUTH #COMMUNITY #CHAT #INFORMATION #ASKQUESTIONS #SUPPORT

In collaboration with:
Community Fund
South Wales and South West Congenital Heart Disease Network
NHS University Hospitals Bristol and Weston NHS Foundation Trust
BHI Bristol Heart Institute

W: www.youthatheart.co.uk
E: contactus@youthatheart.co.uk
@youthatheart22

Charity no: 1158249

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 2022**, please contact Rachel.Burrows2@uhbw.nhs.uk

We welcome:

- Patient/family/staff/team stories
- Clinical news/updates
- Events
- Network related issues
- Anything else you think might be relevant!

The newsletter will be published twice a year.

Sign up for free

Join our mailing list today to receive the SWSW CHD Network newsletter directly to your inbox. Send your email address to Rachel.Burrows2@uhbw.nhs.uk requesting our newsletter