# Newsletter



Updates from your CHD Network

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# Introduction from our Clinical Director Dr Stephanie Curtis

I am delighted to welcome you to the Summer 2025 edition of the South Wales and South West Congenital Heart Disease Network newsletter!

This issue is, as always, full of our usual updates on clinical teams and educational events and a focus on some of the service developments within our region.

First and foremost, however, we said goodbye to Sheena Vernon after more than 20 years as a Clinical Nurse Specialist in Bristol. Sheena has been nothing but short of a legend in ACHD nursing, a trailblazer, and a leader. I have had the pleasure of working with her for all that time and she taught me everything I know about how to look after post-op patients! We are fortunate to still have her working with us on the Network team as Lead Nurse as she continues to provide leadership and mentorship across the Network.

In terms of service development, I was delighted to be part of the new ACHD clinic in Bath. Outreach clinics are so important in reinforcing the links with general cardiology and ensuring that local patients have a footprint in their own hospital. It also allows the local cardiology registrar to gain exposure to ACHD; they always find it an interesting day. As for the patients, they were thrilled to be able to be seen on their own doorsteps. This clinic has been a very long time in the planning. A special shout out to Dr Raveen Kandan, Clinical Lead for Cardiology at the Royal United Hospital in Bath who finally made it happen.

Our patient story and photography competition are heart-warming this season. I hope you enjoy reading about Jack's adventures and the photography shows the natural beauty of the geography in our part of the UK.

There has been lot of change within the Bristol and Cardiff paediatric cardiology consultant staffing groups, but several permanent appointments have been made recently. We look forward to formally welcoming these new members of staff over the coming months. Hopefully, this stability will give parents and carers consistency in who will be looking after their child.

Dr Stephanie Curtis Clinical Director, South Wales and South West CHD Network Your South Wales and the South West Congenital Heart Disease Network is here to support CHD patients of all ages throughout their cardiac journey, as well as their families/carers and the staff who are involved in CHD care across your Network.

Your Network connects all of the hospitals, services, staff, and patient/family representatives from across South Wales and the South West of England.

Together we aim to deliver the highest quality care and experience for our patients.

The Network is also part of a national group of congenital heart

Networks.

#### Network Team Key Contacts

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

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

Lead Nurse: Becky Lambert Becky.Lambert@uhbw.nhs.uk

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

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



# New ACHD clinic at the Royal United Hospital, Bath

By Dr Stephanie Curtis, ACHD Consultant Cardiologist, and Becky Lambert, Network Lead Nurse.

We are delighted to report that on 7<sup>th</sup> May 2025 we were able to facilitate provision of the first ACHD clinic at Bath Royal United Hospital (RUH). Jack, pictured right with Becky Lambert, was pleased to be one of the first patients to attend the clinic.



Previously, RUH has only been able to provide paediatric care for patients with congenital heart disease, and following transition to adult care, patients from Bath and North East Somerset then had to be followed up in Bristol, which was a long journey for some. The RUH was the only Trust in the South West where there was no ACHD clinic aligned with paediatric cardiology.

Clinical Lead for Cardiology at RUH, Dr Raveen Kandan, pioneered for some time to support this project and with the help of Bradley Isaac, Cardiology Manager, funding was approved.

The clinic was delivered by Dr Stephanie Curtis, visiting ACHD Consultant Cardiologist from the Bristol Heart Institute (and Clinical Director for the Network) and supported by local cardiology specialist registrar, Dr James Tomlinson. On this occasion, nursing input was provided by Becky Lambert (Network Lead Nurse), but in the future Bath is hoping to build a nursing role to support these patients, with support from the Network.

The first clinic was a success. Steph and Becky were warmly welcomed by the local team (see group photo below), who all worked very hard to make the day run smoothly. The patients seen that day really appreciated being reviewed locally. This is an important step forward in our aim to provide equity of care for patients with congenital heart disease across our Network.

Royal United Hospitals Bath

Photo from left to right:

Sue Davey, Lisa Parker, Freya Henry, Dr James Tomlinson, Dr Stephanie Curtis, Becky Lambert, Dr Raveen Kandan



#### Dental care in Cornwall

By Nina Worrin, Paediatric Cardiac Nurse Specialist, Royal Cornwall Hospital.

The Royal Cornwall Hospital team recognise the significant lack of NHS dental service provision across the county and the implications of this for some children under the cardiology service. After investigating possible ways to improve upon this they have been working with dental care providers 'Smile Together'.

The 'Smile Together' team have recently attended Royal Cornwall Hospital alongside a Bristol visiting cardiology clinic, where they saw children attending their outpatient appointment and offered a basic screening exam, advice on teeth brushing, oral hygiene and dietary advice, in a professional, child friendly, no-fuss environment!

Dental therapist, Natalie Peary (pictured below), and dental nurse, Jill Andrews, received fantastic feedback from patients and families, and it was proven to be extremely beneficial.

Natalie says, "The overall focus of these screening days is to help promote excellent oral hygiene as this is a huge factor when preventing infective endocarditis. By carrying out a very basic dental screening we were able to determine whether a referral to the community dental service should be made for children without a family dentist. Bringing our teams into the hospital setting means we are limiting the need for travelling and reducing time away from school and work."

The aim going forward is to continue collaborative working, so families have access to dental screening and advice alongside their cardiology clinic appointment.





## News from the Adult Cardiac Nurse Specialists

By Rachel Wyatt, ACHD Cardiac Nurse Specialist, Bristol Heart Institute.



Thanks to Sheena Vernon on her 23 years as an ACHD CNS

February saw the end of an era, with Sheena Vernon retiring from her Clinical Nurse Specialist (CNS) role at the Bristol Heart Institute. Sheena played a pivotal role in creating and developing the ACHD service in Bristol since she began working as a CNS in 2002.

Sheena's contributions to the team have been invaluable, we have all learned so much from her. Sheena will be missed by her BHI colleagues as well as the countless patients and families who she has advocated for and supported over the years. We are happy to know that Sheena is continuing with her Lead Nurse role for the Network and is nearby when her wisdom is needed!



Successful opening of the new Young Persons Room at the BHI

The Young Person's room was officially opened on 15<sup>th</sup> May at the Bristol Heart Institute. The development of the room from a storage cupboard into a haven for young patients has taken many years of negotiations, applications for funding and working with contractors.

The result is worth the effort and will be appreciated by young patients who want to relax in a safe space, away from the ward environment.

The room is equipped with a TV, play station and sensory equipment, and is a dedicated space for young people aged 16 to 24 years who are in hospital as an inpatient or an outpatient waiting for appointments/rests.

It has been developed holistically to support young people's mental health and wellbeing and provides a safe space for patients with learning disabilities or neurodiversity.



Photo left to right: Angela Jackson Owen Ainsley Rachel Wyatt Danielle Poole Mary Beadle Xander Patel-Cook Hannah Willians Sheena Vernon



CNS photo above, left to right: Mary, Danielle, Rachel, Hannah.

#### Enhancing skills and learning

Hannah, Danielle and Rachel have been continuing along the Masters pathway studying Masters modules in leadership, physical assessment and pathophysiology respectively.

Being able to develop skills and expertise in these areas is a vital part of the CNS role and helps to ensure that patients are receiving the best care possible.





In South Wales, following a competitive process, Sarah Finch (ACHD Clinical Nurse Specialist) has been successful in obtaining a Florence Nightingale Foundation (FNF) Leadership Scholarship. This is a national programme for nurses and midwives.





## Paediatric Cardiac Nurse Specialists

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

Healthcare plans for children with CHD starting school It's around this time of year that we are contacted by parents and schools regarding Health Care Plans for children starting school/moving schools in September.

For many children who have had corrective surgery, a full healthcare plan may not be required. It may be that the school just needs some reassurance that there are no additional requirements for these children. We are more than happy to offer advice on whether a plan would be appropriate.

Children with a more complex diagnosis would benefit from having a more formal healthcare plan to enable the school to adequately support their child's needs, and we are happy to provide information to families and schools to support this.

#### Dental checks and finding a dentist

Just a reminder that all children who are due to have cardiac surgery should have an up-to-date dental check to ensure the risk of endocarditis is as low as possible. It is also recommended that any children with a CHD diagnosis are seen by a dentist every 6 months.

If you are having problems in finding a dentist, please do let your local Consultant Paediatrician with Expertise in Cardiology (PEC), Local Cardiac Nurse or Clinical Nurse Specialist team know. For more information on endocarditis and healthy teeth please scan the QR code below.



To access the patient information leaflets, scan these QR codes:







## Transition & Transfer Evenings for Young People with CHD

On the 4<sup>th</sup> March, the Bristol ACHD and Paediatric teams held their first in person Young Persons evening at the Bristol Heart Institute. This originally started in 2005 but shifted to online due to the COVID-19 pandemic.

This is an opportunity for young people with CHD (aged 15 years +) and their families/friends to meet the Bristol ACHD team in preparation for their transfer from the paediatric service to the adult centre at the BHI for their ongoing care in the future. The evening is open to all patients across the Network.

The March event was attended by 14 young people with CHD. The team presented an overview of the adult centre detailing what to expect during the first appointment. They then offered a tour of the BHI in small groups and there was time for questions and signposting to support. ACHD Youth Worker, Xander, also joined the event. It was great to see so many people attend from across the region.

Feedback was very positive! Having a tour of the BHI proved to be very popular, with particular interest in the newly refurbished young persons waiting area in BHI outpatients (C503) and the new young persons room on level 7.



Moving forward, the Bristol paediatric and adult CHD team plan to host one virtual and one in person event each year. The next will be held virtually on 16th September 2025.

We would encourage any of our paediatric patients (aged 15 years +) throughout the Network who are going to need lifelong follow-up care to join this event. It's a great opportunity to meet the adult team and ask any questions you may have about the process of transition.

Please contact your Paediatric Cardiac Nurse Specialist team if you would be interested in finding out more (see back cover for contact details).





## **Education and training**

One of the Network objectives is to support and promote training and education opportunities for our healthcare professionals involved in the care of patients with congenital heart conditions. Details of training and education events can be found on the Network website (www.swswchd.co.uk).



#### Thank you to those involved



#### ACHD Medical Training Programme, May 2025

A successful online regional ACHD medical teaching day was held in May 2025 focusing on an introduction to ACHD, hosted by Dr Lisa Mcclenaghan, locum ACHD Consultant Cardiologist (BHI) and the Network. The online format made this as accessible for people as possible.

The aim of the event was to equip and increase the expertise of cardiology trainees, clinicians, nurses and physiologists in all areas of the Network, particularly from the peripheral hospitals, in the management of ACHD. Many of our patients live remotely and therefore may not present to the specialist centres first (Bristol and Cardiff), so this therefore promotes continuity of care in the Network.

60 delegates attended on the day primarily from across the South Wales and South West England region, but also from as far as Northern Ireland, London and Liverpool. The programme covered basic physiology and epidemiology of ACHD, congenital cyanotic heart disease, bicuspid aortic valve and aortopathy, univentricular circulations, arrhythmia, heart failure and endocarditis. Feedback was really positive and aligned with the aims of the day.

"This was an excellent overview of ACHD... case studies provided throughout were really useful to relate back to clinical practice"

"Really useful and pragmatic talks which will impact my day-to-day work"



#### Psychology Network Day, June 2025

An online CPD psychology day was held in June 2025 with over 40 delegates, led by the Clinical Psychology Leads in the Network. It was aimed at professionals working with paediatrics and adults in cardiology, critical care and CHD. The day covered topics such as being proud to step out of the norm, neurodiversity, artificial intelligence, reflecting on power and fear. Giving the opportunity to hear from patients, clinicians, and family members about their lived experiences; and to reflect and connect with colleagues in break-out rooms.



#### Transition Study Event, July 2025

The bi-annual transition education programme continued, with an event in July featuring new talks on developing transition and transfer to adult services across the CHD Network, the patient journey of a young adult with CHD and Downs Syndrome (see page 11), and patient and family preparation for transition and transfer of complex young people.



#### What's coming up?

- ☐ ECHO ACHD webinars, dates throughout the year online
- ☐ ACHD Study Day 7<sup>th</sup> October 2025
- ☐ British Congenital Cardiac Association (BCCA) annual conference 3<sup>rd</sup> & 4<sup>th</sup> November 2025, London



## SWSW CHD Network NHS Future Platform

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

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

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

Do also check out the 'Events' calendar on the Network website for upcoming events www.swswchd.co.uk



#### Wales and West Acute Transport for Children

By Carrie Murdoch, Service Sister, WATCh.

#### What is WATCh?

The Wales and West Acute Transport for Children service (WATCh) is a team that provides critical care clinical management advice and inter-hospital intensive care transport for children in South Wales and South West England.

WATCh is a joint partnership between two paediatric intensive care units based in Cardiff and Bristol. The team is funded on a 24-hour basis and can provide support using teleconferencing and video calling platforms. This includes the ability to facilitate discussions directly with the specialist paediatric cardiologists from across the Network.

#### A year in numbers

In the year 2024-2025, WATCh received 1,311 referral calls	765 resulted in clinical advice only
	520 resulted in a WATCh transfer.
	72 of these referrals were related to an ante-natal or post-natal cardiac diagnosis.



For further information on the WATCh team, please visit; <a href="https://watch.nhs.uk">https://watch.nhs.uk</a>

#### Who are the team?

The WATCh consultant will determine the team composition at referral. WATCh includes medical staff from Paediatric Intensive Care, Anaesthesia, Paediatrics, Emergency Medicine, and Advanced Transport Nursing and specialist Nursing Staff. Each transfer is discussed collaboratively between the referrer, WATCh, and the accepting critical care consultant, with ongoing access to WATCh consultant advice. WATCh use a dedicated ambulance and driver for all transfers.

If a critical care transport is required, the WATCh team will liaise with the referring clinical team to ensure that effective stabilisation is commenced and continued whilst the team is travelling to the bedside from the new SWR base at the junction of the M4 and M5 motorways.

#### What happens on arrival?

On arrival, the team will continue the work started at the point of referral to stabilise and then transfer these patients to their nearest Paediatric Intensive Care Unit (PICU) in either Cardiff or Bristol or, into a High Dependency Bed depending on the acuity of illness. If no beds are available within region, WATCh will source a bed in the next nearest PICU that provides the support the child needs. We aim not to separate parents from their child during transfer and WATCh has the ability to accommodate one parent/carer in the ambulance although, if we are travelling by air, this is not always possible.

#### What happens at the destination?

Finally, when we reach our destination, we handover the care to the receiving centre using a comprehensive multidisciplinary approach thus ensuring that we provide a holistic assessment of the child.



## A warm welcome

## Introducing Dr Elinor O'Neill, **ACHD Consultant Cardiologist**



In June 2025, we were delighted to welcome Dr Elinor O'Neill as a new Consultant Cardiologist in Adult CHD based at University Hospitals of Wales.



#### What are your interests?

I am a specialist in treating adults with congenital heart disease. I trained in adult congenital heart disease at the Bristol Heart Institute and at the University Hospital of Wales. My interests include echocardiography and cardiac MRI. I am passionate about delivering care closer to home, and in ensuring that adults live well with congenital heart disease.



#### 【 |■】 Tell us about your training?

I studied medicine at Imperial College London and graduated in 2013. I went onto complete my postgraduate medical training in South Wales.

Did you know...? Dr O'Neill is also a fluent Welsh speaker.

Conference round-up: Toronto ACHD, June 2025: 34th Annual International Symposium on Adult Congenital Heart Disease

I recently travelled to Toronto (Canada) for this fantastic symposium hosted by the Toronto ACHD programme on behalf of the International Society of Adult Congenital Heart Disease (ISACHD). I was enticed by this year's conference's theme, "Overcoming the Challenges".

Sessions that particularly resonated were "challenges in caring for patients with congenital heart disease" with talks on occupational counselling and developing palliative care services. Dr Daniel Tobler, a Cardiologist from Switzerland, gave an engaging talk on exercise counselling in patients with ACHD. His top 3 recommendations were hiking, cycling and swimming. Singing was recommended too! Our patients are increasingly undertaking resistance training, and a dedicated talk was given about the benefits of resistance training for patients with congenital heart disease. There were also interesting sessions on pregnancy, the future of congenital cardiac surgery, the Fontan circulation, and the organization of future congenital heart disease services. It was great to meet colleagues old and new.

Toronto itself is a vibrant and wonderfully diverse city, and the cityscape is amazing too. Away from the CN Tower and the Rogers Stadium, the Kensington Markets and Distillery district are worth a visit.

My biggest take home was what we are doing in the UK, isn't particularly different to our North American colleagues. I am proud to be part of the SWSW CHD Network, and lots of the work done by colleagues in the Network, such as moving care closer to home, access to psychological support and a superb exercise pilot overseen by my colleagues in Cardiff are exemplars of this.

It was a fantastic way to kick-start my post in Cardiff, and I will have to start saving for the next trip!





#### Update on team changes

At the University Hospital of Wales (Cardiff), we are pleased to welcome back Dr Jane Bromilow, Consultant Cardiologist (paediatric CHD). In August, we will say goodbye to Dr Nadia Hajiani, Consultant Cardiologist. We congratulate Dr David Blundell, who is currently working as a locum consultant cardiologist in Bristol, to the substantive post with the team in Cardiff.

We also welcomed back Bethan Shiers, ACHD Clinical Nurse Specialist, and Beth Corris, ACHD administrator, in South Wales.

At the Bristol Royal Hospital for Children (BRHC), we welcomed Dr Hiyan Mahmoud, Paediatric Consultant Cardiologist, and soon Dr Silvia Caroli, Paediatric Consultant Cardiologist in August.

We also welcomed Dr Jodie Canning and Dr Caitlin Black, two new Clinical Psychologists working in paediatric cardiology and the paediatric intensive care unit at the BRHC.

Welcome to new BRHC Clinical Nurse Specialist team administrator, Jayne Oram, who is job sharing with Chantelle Shapcott.

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



## Network update

By Michelle Jarvis, CHD Network Manager

It has been a busy few months across the Network with a flurry of education and training events for Network professionals held in late spring / early summer, which were well attended and positively evaluated. Thank you to all the organisers and speakers for delivering such valuable events.



The Network team have recently enjoyed supporting the Level 1 (Bristol) paediatric and adult self-assessments against the national CHD standards, particularly in hearing about the successes and innovations of both services. We thank both teams for their excellent engagement and very much look forward to working together on next steps to improve compliance.

Following the South West of England Level 3 centre self-assessments held last year, it has been really positive to receive updates from some of the services sharing progress made against some of the identified areas of challenge. Much of this progress has been in supporting development of the CHD workforce teams across the region to ensure they are able to deliver high quality services to patients. Some centres have even been able to secure additional funding to support workforce expansion and the purchase of key equipment.

Our work programme for 2025/26, developed in collaboration with Network stakeholders, has now been finalised and signed off by NHS England. The Network team look forward to getting stuck into some new areas of work whilst continuing with longer term projects such as transition and transfer of care. You can see a summary of our workplan on the Network website (<a href="www.swswchd.co.uk">www.swswchd.co.uk</a>). We are always interested in suggestions for new projects and workstreams where there may be improvement opportunities, so, please do get in touch if there are any areas you would like us to further explore (<a href="microsummirror">microsummirror</a> and workstreams where there may be improvement opportunities, so, please do get in touch if there are any areas you would like us to

#### Getting involved in research for CHD

Professor Craig Williams, Director of the Children's Health and Exercise Research Centre at the University of Exeter

Researchers at the University of Exeter are conducting a survey to understand attitudes on exercise in day-to-day life and around exercise as a diagnostic test in adults (older than 16 years old) living with a congenital heart disease (a cardiac condition present from birth).

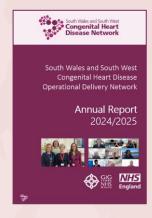
The South-West Congenital Heart Disease Network have partnered with their team to share the questionnaire with your group. This is fully anonymous and does not collect any sensitive information. The goal is to learn what people with congenital heart disease feel is most important to them when it comes to exercise, to improve future research and medical care. The link to the online form is below as well as a QR code. The closing date is: 01/09/2025.

 $\underline{https://forms.office.com/e/MqLs1tUV0a?origin=lprLink}$ 





## CHD Network 2024/25 – Read all about it!



The Congenital Heart Disease Network Annual report for 2024/25 has been published.

Find out about the key achievements and challenges for the network in its ninth 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.swswchd.co.uk) to read it in full.

## Network dates for your diary!

Key Network meetings:

Wednesday 6<sup>th</sup> August 2025: Network Board

Monday 22<sup>nd</sup> September 2025:

Level 1 & 2 Strategy Day

Tuesday 25<sup>th</sup> November 2025: Network Board & Clinical Governance



## Staff Photographic Competition #7:

## 'Landscapes across the Network'

Throughout May 2025 we received photos from CHD Network staff, who have taken photos whilst out and about, on a trip away or during their commute to work. To see all the entries and also to peruse the galleries of previous entries, please visit the Network website:

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

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.

The winner is 'commute to work in South Wales'-photographed by Dr Helen Wallis, ACHD Consultant Cardiologist and Clinical Lead, Cardiff.





### Runners Up



'Spring and sunset across the Cornish north coast'
photographed by Dr Georgina Ooues, ACHD Consultant Cardiologist,
Royal Cornwall Hospital.



'Sunet at Appledore' photographed by Sharon Russell, Local Nurse Specialist, Royal Devon University Hospital (Northern site).

# Patients at the heart of our Network: Jack's story



By Kareen, Jack's mum

A super easy pregnancy and remarkably quick birth lulled us into a false sense of security, less than 24 hours later our blissful bubble burst. First, we were told Jack probably had Downs syndrome, and after more tests than we could keep up with, a problem with his heart. It's amazing how Downs syndrome pales into insignificance when a consultant tells you your child has a significant cardiac problem.



When Jack was three days old, he was transported by ambulance to Bristol for a more detailed scan, there we found out the full extent of his heart defect. Tetralogy of Fallot with a full AVSD meant nothing to us at that point. We were told "if he survives the next three weeks it's 50/50 that he'll make his first birthday."

Not only did he survive those three weeks, Jack became stable enough to spend his first Christmas at home, a Christmas that was special and terrifying in equal measure.

By mid January, Jack was struggling and eventually ended up being blue lighted to Bristol from Taunton where he had the first of two BT shunts. The second was on his dad's 40th birthday, another collapse and blue light trip to Bristol where they found a blood clot in his first shunt. it was removed and a second shunt put in, we took Jack home less than a week later, just in time to celebrate his first birthday. He would beat the odds, and we were becoming used to Jack keeping us on our toes.

The next four years were a waiting game, not knowing if a repair was possible, just keeping Jack as well as we could, making the most of every day and hoping for a miracle.

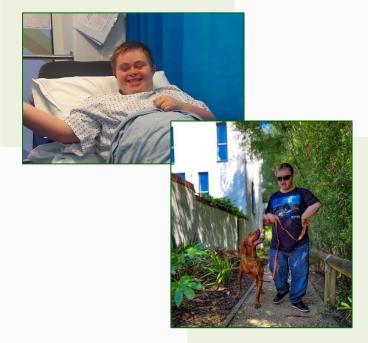
That miracle came when Jack was five years old, once more in Bristol, Jack was facing his biggest challenge yet. A cardiac catheter picked up on a problem that lowered Jack's odds of making it through the repair surgery dramatically, we were terrified, and, if it hadn't been for the brutal honesty of an incredible anaesthetist we may well have cut and run taking our precious boy with us. if we had, we would have lost him within weeks, thankfully we stayed.

Our trust in Jack's brilliant surgeon and his team paid off, after 9 hours of surgery, and a few complications our boy was in recovery, and for the very first time we saw him looking pink, the blue nails were gone. Less than two weeks later we took him home.

Jack has thrived since his repair. He will always be a cardiac patient, but that doesn't mean he will always be ill. For most of the time Jack is strong, happy and loves nothing more than walks with his beloved dogs, and spending time with his sister, mainly so he can tease her as only a little brother can.

Jack has brought us so much, yes there's been fear, but there's also been joy, laughter, and so much love. He has taught us to concentrate on the positive every day, face the hard bits together and never miss a chance to make beautiful memories.

Memories that would not have been possible without the incredible skill of the medical team that has supported us at every step, and who we are so very grateful to have with us.





#### Useful contacts

We provide life-long support and advice to patients and their families throughout their whole journey with us.



Adult CHD Clinical Nurse Specialist Team (Bristol)

Available: Mon to Fri, 8am to 4pm Email: bhiachdnurses@uhbw.nhs.uk

CNS Telephone: 0117 342 6599

BHI Outpatient Department: 0117 342 6638 Cardiac Admissions Office: 0117 342 9444 Pacemaker/ICD advice line: 0117 342 6515

Adult CHD Clinical Nurse Specialist Team (South Wales)

Available: Mon to Fri, 9am to 4pm Email: achdnurse.cav@wales.nhs.uk CNS Telephone: 029 2184 4580



Appointments & non-clinical queries: 029 2184 3892 or via achd.cav@wales.nhs.uk https://cavuhb.nhs.wales/our-services/adult-congenital-heart-disease-achd-

service/about-the-adult-congenital-heart-disease-achd-service/



Paediatric CHD Clinical Nurse Specialist Team (Bristol)

Available: Mon to Fri, 8am to 4pm Email: cardiacnurses@uhbw.nhs.uk CNS telephone: 0117 342 8286

Appointment co-ordinator: 0117 3429281 Surgical co-ordinator: 0117 3428977

For any clinical queries and emergencies (out of hours), please contact Dolphin Ward via switchboard (0117 342 0000).

Paediatric CHD Clinical Nurse Specialist Team (South Wales)

Available: Mon to Fri, 8am to 4pm

Email: PaediatricCardiac.Cns@wales.nhs.uk

CNS telephone:

Cardiff & Vale 029 2184 5184

Bridgend, Merthyr, Rhondda 029 2184 7021

Gwent 029 2184 5524

Swansea and West 029 2184 4753

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

Fetal care 029 2184 1746

Appointments and non-clinical queries: 029 2184 4749



#### Want to know more?

The Network website is for patients, families and clinicians.

We have information on:

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

Please share your feedback on our newsletter by scanning this QR code with your phone or via the link

https://forms.office.com/r/dSLx5mAK15



#### Thank you for reading!

If you have any stories or ideas, you would like to share for the next edition in New Year 2026, please contact CHDNetworkSWSW@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 CHDNetworkSWSW@uhbw.nhs.uk requesting our newsletter.