South Wales and South West
Congenital Heart Disease Network

Spring 2021
Issue 9

Newsletter

Inside the Spring 2021 edition

Clinical Director’s Introduction

Welcome to our spring 2021 edition of the South Wales and South West Congenital Heart Disease Network newsletter!

I am sure many of you will have paused and reflected on the day we observed a full year of this pandemic. I recognise the challenges and sacrifices many have had to endure and the painful losses some have witnessed first hand.

We now enter a phase of restoration and, hopefully, a return to “normality”. Only now do we see the return of our lead nurses, Sheena and Jess, back from redeployment to support our adult services.

Our network team played a pivotal role in bringing all the UK Congenital Heart Networks together “virtually" throughout this time, harmonising advice on COVID-19 to health care leaders and providing mutual support for each other.

Providing information has been key throughout and I defy any of you not to raise a little smile at the Truro team cardiac outpatients information board! (see page 7). We touch upon the important issue of self-care and mental health, so please review these resources. I’m also very proud of more innovative work such as the cardiac nurse webinars and our pharmacists on harmonising prostaglandin therapy across the network.

Building for the future is important and I am delighted to introduce Dr Georgina Ooues, Consultant Cardiologist at the Royal Cornwall Hospital (see page 13). Georgina is, I believe, unique as the first fully accredited ACHD consultant appointed to a district general hospital in the UK. Other new colleagues include Kindre Morgan and Emma Benger to the Welsh CNS teams, Dr Muhammad Addin in Bath & Dr Simon MacDonald in Cardiff. Welcome to you all.

I would like to take this opportunity on behalf of the network to thank David Mabin, who has stepped down from his role as network board chair, after 4 successful years in post.

I hope you enjoy reading our Spring offering!

Keep safe

Dr Andy Tometzki
Network Clinical Director

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.

Network Team Key Contacts

Clinical Director: Dr Andrew Tometzki
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Lead Nurse: Sheena Vernon
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Lead Nurse: Jess Hughes
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Network Manager: Cat McElvaney
Cat.McElvaney@uhbw.nhs.uk

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

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

COVID-19: Getting Support
We are in this together

Looking after our emotional and physical wellbeing at this time is really important. It's normal to feel anxious or worried right now, whether that's about our own health or that of a family member or friend.

Here are a few steps for keeping yourself well during this pandemic.

Connect with others – It may not be possible to physically be with others at this time, but checking in by text, video calls and phone calls are all ways to keep connected. Consider planning online activities, such as quizzes, games.

Stay active – gentle movement or exercise can help us to feel more relaxed and unwind. NHS staff can access 'doing our bit,' a free exercise platform for NHS staff. https://www.fit4thefight.org/nhs-members-area

Be mindful – mindfulness can help us feel more focused in the present moment, and has been shown to help with anxiety and depressive symptoms. There are many excellent free online resources that you can use.

For help and support with how you are feeling, a good place to start is the NHS every mind matters website which has some helpful tips and advice online to support us through this time, whether that's concerns you may have about your finances, or ensuring that you or others have the supplies that you need. For NHS staff, you may wish to contact your organisation's wellbeing team.

Make time to rest - Make sure you find time just for you. You could use the tips above, e.g. taking time for mindfulness or going for a walk.

Seeking further support

Have you visited our network COVID-19 information webpage? There are lots of supportive resources available www.swswchd.co.uk.

If you would like to use a self-help guide for any mental health difficulties you may be experiencing, e.g. anxiety, anger, low mood you can find them at https://overcoming.co.uk/7/Home

You can find further ideas for managing the emotional and social impact of coronavirus on the Mind website https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/

If you have concerns about coronavirus specifically related to your health issues then you can contact your medical team or look at national health websites for specific conditions, such as:

British Heart Foundation: www.bhf.org.uk/

Somerville Foundation for Congenital Heart Disease: https://thesf.org.uk/

UK Government Website: www.gov.uk/coronavirus

NHS Website: www.nhs.uk/conditions/coronavirus-covid-19/

Supporting you and your child's health and wellbeing during COVID-19

To think about how to support young people at (home) school and with their emotional health, there are a few thoughts and ideas in the infographic below.

The impact of COVID-19 will be different for everyone and how it affects you and your child may also change over time. You may at times have challenges with schooling, balancing work and life and how you are feeling emotionally.

You may also be finding out about some areas of your life that you like more as you may have closer relationships with your children or are enjoying working from home more. It can be helpful to reflect and think about what questions and worries you have that you would like support with and also some of the things that you would like to keep in your life that you have appreciated.

As your cardiac network team we know that how you and/or your child access cardiac care and treatments may look and feel different too.

Did you know …

'Psychological first aid' training is available from Public Health England. This is aimed at supporting children and young people aged up to 25 who have been affected by COVID-19.

Find out more at https://www.futurelearn.com/courses/psychological-first-aid-for-children-and-young-people

Support booklets

The Bristol Psychological Health Services team have been working with adults, families and young people to put together some support booklets.

The booklets cover questions around coping with worries around COVID-19, knowing someone with COVID-19 or coming into hospital, as well as strategies for parents/guardians to support themselves and their children.

Visit the COVID-19 page on our network website to find a link to the booklets for adults, parents and young people.

The British Psychological Society has also produced a useful resource on managing uncertainly in children and young people: advice for parents during the Covid-19 pandemic.

Let's hear from...

The Somerville Foundation

Supporting young people and adults born with a heart condition

COVID-19 has affected everyone but those who have congenital heart disease have been under a much greater level of concern and even anxiety.

- Membership scheme - We have made sure as much information, agreed by the clinicians nationally, was circulated to all those who interact with us. We are sure, however, that many adults with CHD have not been able to benefit as we don't know who they are and so we launched our membership scheme in February.

- The closed Facebook page is a private group for those with ACHD and a place for confidential discussion and support. This is full of very useful discussions providing much comfort and a place to turn.

- As the vaccination programme rolls out the questions have turned more to whether they should or should not be 'clinically extremely vulnerable' or just 'clinically vulnerable' and what the vaccination was like to have.

- Our webinars addressing these concerns are going down particularly well, here is a link to watch a recording of the January webinar.

- Our Covid Support Fund can provide a little extra support for those finding themselves in difficult circumstances for example struggling to pay bills, buy food, or buy items that can make a difference and improve everyday life.

  We have grants available up to a maximum of £500 which can make a huge difference to the life of someone struggling and we have received some really nice thank you messages telling us what a difference this has made. We still have funds available and look forward to hearing from those that need little extra support.

Thank you
Pause · Reflect · Recover

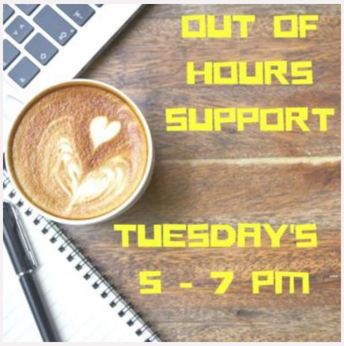
We want to say a big thank you to all the amazing NHS staff who have continued to provide care and compassion during this very difficult time.

Youth @ Heart update

Youth @ Heart's support workers, Xander and Monet, are available to support young people with CHD and raise awareness.

During COVID-19, they have been running virtual catch up sessions, gaming sessions (via mobile phones) and also a support service for young people aged 15 to 24 years who would like to reach out for advice, a rant, or to talk about what they are going through.

"We are always happy to chat, try and find answers, or signpost to other organisations. Our focus is to try to make this difficult time easier to cope with. Please do get in touch if you need help, watch our Facebook pages for guidance, suggestions and fun activities."



YOUTH @ HEART

Are you aged 15-24 with Congenital Heart Disease?

We can offer you and your family support. Please get in touch if you would like to chat.

- Events & activities.
- Out of Hours support
- Guidance through the transition stage.
- Inpatient and Outpatient support
- A chat about anything - in hospital or in the community.
- We are here to support the whole family.
- Signposting to specialist support services.

Contact Us

Monet	Xander
Community Youth & Family Worker	ACHD Youth Worker
07578 399916	07832 668907
monet@youthatheart.co.uk	xander@youthatheart.co.uk
facebook.com/monet.heart.127	facebook.com/xander.heart.18

Funded by Youth@Heart and The National Lottery

Read all about it!

Royal Cornwall Hospital's New Paediatric Cardiology Outpatients Information Board

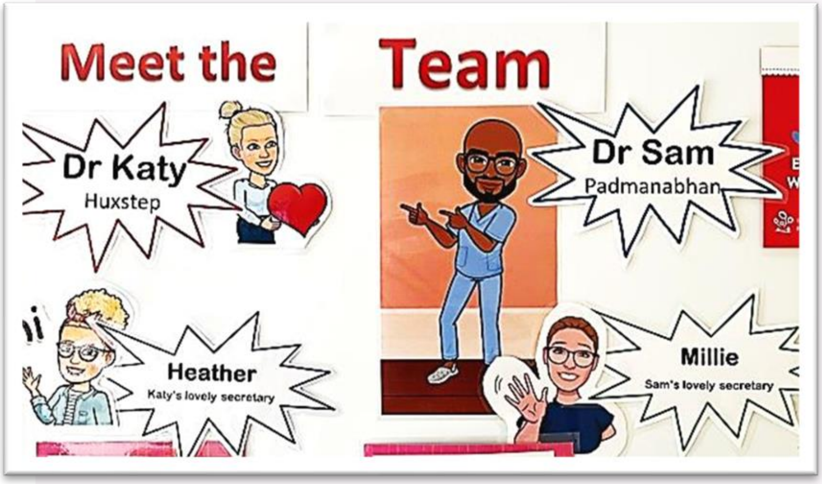
In Cornwall there are over 1000 children with some form of congenital heart disease. The paediatric team at Royal Cornwall Hospital are passionate about ensuring these families have the knowledge and understanding they need, and know how access to the huge amount of information and support available to them.

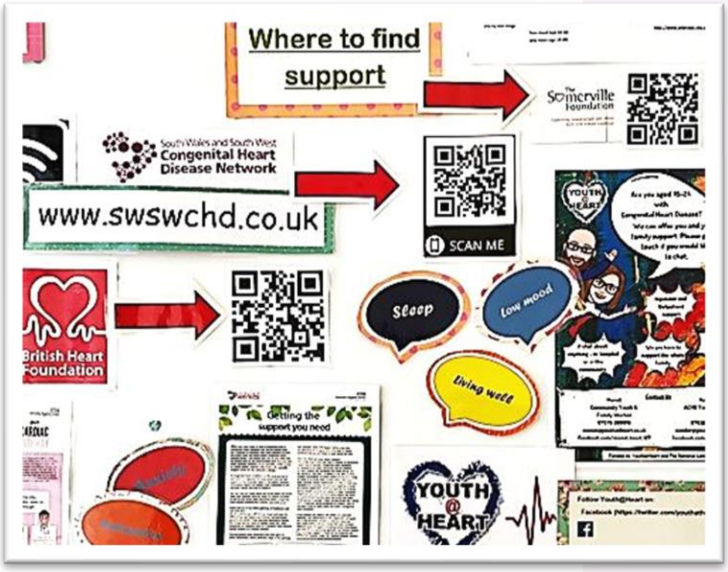
Therefore, in the Gwithian outpatient waiting area they have created a fun, vibrant, child friendly cardiac information board with advice on how and where to find support, resources and fun facts here and more!

Let's have a closer look!

The plan is for the board to be an ongoing project, with relevant topics changing every few weeks to keep it interesting - but the main reason being there is too much information to put on at once!

Currently the board is touch free – with direct links via QR codes to relevant online resources, but the hope is that it can eventually be more interactive with activities, mini quizzes and colouring for younger children.





The team aim to work together with families to ensure they feel involved in their care, and value their opinions and ideas on the cardiac service in Cornwall – what works well and what could potentially improve the service in the future.

They have therefore also created an online survey to gather patient feedback on their experiences. Watch this space!

With special thanks to Nina Worrin, paediatric nurse and cardiac link nurse for Gwithian Outpatient Department, and Dr Katy Huxstep, Consultant Paediatrician with an Expertise in Cardiology.

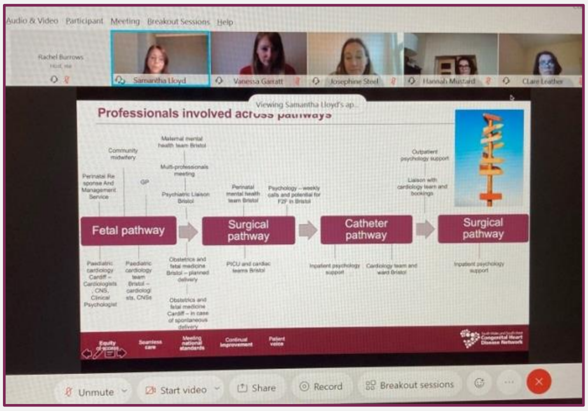
Education and training

2021 Virtual Psychology Network Day – held 2nd February

The purpose of the virtual psychology network day was to continue to build a network and connect clinicians together, as psychologists who may see cardiac patients are in a range of places (adult and child community mental health teams, health psychology teams and specialist cardiac teams). Psychological support might also come from counsellors and therapists.

The aim is to connect all staff who may provide support and provide them with skills to manage common issues and know how to link into specialist psychological cardiac services when needed.

Next steps: The plan for 2021/22 is to build a map, pick up themed training and develop start and finish groups around key projects.



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 soon?

- Fetal webinar series
- Paediatric Cardiac Nurses – 2021 new webinar services. Delivered by nurses, for nurses.
- PEC study day, 14th May 2021

PEC platform

We are currently working together to build a central platform to support PECs across the South Wales and South West.

- ✓ Clinical and non-clinical resources
- ✓ Sharing information
- ✓ Forum for discussion
- ✓ Sharing contacts

> *"From a service development perspective, it's helpful in creating closer links with the regional services. Much easier and less stressful than the long drive to Bristol. It was co-ordinated and flowed well"*

> *"The range of speakers was brilliant."*

> *"Lots of useful information and a great way to meet colleagues from across the South Wales and South West CHD network, hear about their work and how we can work together for the benefit of our patients."*

Calling All Paediatric Nurses!

2021 New Webinar Series

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

Each **90 minute webinar** offers: a **teaching presentation** +

advice and guidance from the Clinical Nurse Specialists +

interactive **Q&A** at the end of each webinar +

The webinars will be available **live.**

+ Wed 24th February.	10:00-11:30.	Normal heart; fetal circulation; PDA; ASD; VSD; AVSD
+ Tues 23rd March.	14:00-15:30.	Rhythms and anti-arrhythmics; 'simple' ICC
+ Mon 26th April.	14:00-15:30.	CoA; TGA; severe PS/AS/TOF; prostin
+ Tues 25th May.	14:00-15:30.	Uni-ventricular palliation; HLHS/HRHS; anticoagulation service
+ Thurs 24th June.	10:00-11:30.	Patient pathway including fetal, surgical and cath
+ Mon 19th July.	10:00-11:30.	Cardiac failure; common cardiac medications (exc. Warfarin)

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

Bristol Royal Hospital
For Children

Prostagladin therapy in infants with duct-dependant congenital heart disease across the network

By Fiona Sinclair, Rotational Pharmacist, and Susie Gage, Lead Paediatric Cardiac Pharmacist , University Hospitals Bristol and Weston NHS Foundation Trust

SITUATION

A patient was retrieved by WATCh (Wales and West Acute Transport for Children Service) transport team (go to https://www.watch.nhs.uk/ for more information) to Bristol Royal Hospital for Children, for surgical assessment. The patient was initiated on Alprostadil, a prostaglandin that is used in infants, to keep their ductus arteriosus patent.

BACKGROUND

The ductus arteriosus (‘the duct’) naturally closes within the first few weeks after birth. Prostaglandins maintain patency of the duct. Alprostadil and Dinoprostone are prostaglandins given intravenously as a continuous infusion, used for duct-dependant lesions, such as Co-arctation of the Aorta.

Dinoprostone is South Wales and South West Congenital Heart Disease (CHD) Network’s choice of prostaglandin and the aim would be that all centres follow our guidance. We try to provide a seamless approach across the entire Network, regardless of location. So, we have written a guideline on the use of Dinoprostone; how to make up the infusion and the monitoring of the patient.

ASSESSMENT

In response to the patient that was retrieved from WATCh, and after discussion with the WATCh team regarding similar experiences, all paediatric and neonatal units in South Wales and South West CHD Network were surveyed, to investigate which centres are using Alprostadil, rather than the Network choice of Dinoprostone. 17 centres were contacted.

The majority of centres are using Dinoprostone, some are unclear of which prostaglandin to use but would seek advice from WATCh or Paediatric Cardiology Consultants at Bristol Royal Hospital for Children, a few are using Alprostadil until existing stocks are used up with the aim to then use Dinoprostone, and a couple are still using Alprostadil.

RECOMMENDATION

All results will be shared with the network board in order to ensure seamless continuity of care across the network and address any outliers of practice. Another action point is to ensure all centres are aware of the network prostaglandin of choice and are aware of where to locate the Network Dinoprostone guideline – this can be found here:
https://foi.avon.nhs.uk/Download.aspx?r=1&did=21048&f=Dinoprostone

The Bristol Royal Hospital for Children external guideline site is currently being updated but the network paediatric guidelines are available at the following link:

http://www.uhbristol.nhs.uk/for-clinicians/clinical-guidelines/

If you cannot locate any medication related guidelines, please contact the network team or Susie Gage, Lead Paediatric Pharmacist.

Who are the WATCh team?

The Wales and West Acute Transport for Children Service (WATCh) is a jointly commissioned team responsible for the safe transfer of critically ill children across South West England and South Wales.

The team co-ordinates the transfer of children into the regional Paediatric Intensive Care Units (PICUs) and High Dependency Units (HDUs) in Cardiff and Bristol.

Find out more at:
https://www.watch.nhs.uk/

WATCh Wales and West Acute Transport for Children

The role of Cardiac Magnetic Resonance Imaging in the assessment of paediatric congenital heart disease*

By Sri Narayan, Consultant Cardiologist, Bristol Royal Hospital for Children

"If you can't see it, you can't fix it…."

This saying is true in congenital cardiology, as in all many other aspects of life. Cardiac imaging is of fundamental importance in congenital cardiology and is used by clinicians in the assessment and care of children with cardiovascular disease.

Echocardiography

This is the first-line cardiac imaging investigation for many cardiac conditions. It is widely available, provides structural and functional information, and reliably reports the required clinical information in most cases. However, if accurate three-dimensional morphological and functional information is needed or if extra cardiac thoracic vessels are to be evaluated, cross sectional imaging in the form of a cardiac magnetic resonance imaging (CMR) or cardiac computed tomography (CT) would be necessary.

Cardiac Magnetic Resonance Imaging (CMR)

CMR has been called the "One Stop Shop" for cardiac imaging. It supplies additive and complementary information to other modalities. CMR can accurately assess all cardiac structures; provide precise anatomical and functional information; and measure flow. There are expanding indications for a variety of congenital and acquired conditions.

It is largely a safe procedure, with no exposure to ionising radiation. Many children as young as six years or less can undergo CMR without the need of a general anaesthetic, with appropriate preparation.

There are exciting developments with CMR which will enable it to play a more significant role in the management of variety of conditions.

Future directions

CMR will continue to play an increasingly significant role in assessment of children with cardiac disease. Some of the recent developments are:

1. **MR Diagnostic and Interventional catheterisation**. This can avoid radiation and can accurately assess flow, in addition to pressures within cardiac chambers. This is useful in the exact assessment of pulmonary vascular resistance. MR interventions are not yet main stream as there are limited availability of MR compatible devices and wires for performing interventions. However, it is rapidly expanding and is a subject of ongoing research.
2. **Fetal CMR**: CMR can visualise fetal cardiac and vascular anatomy, quantify fetal blood flow, oxygen saturation and haematocrit. This improves our understanding of fetal development and impact of disease.
3. **Artificial intelligence and deep learning methods** are revolutionising the performance, image reconstruction and interpretation of CMR and holds promise in making CMR faster and more accurate*

*for full article and references please email Sri.Narayan@uhbw.nhs.uk.

Scans – find out more!

Your doctors might send you for scans to help them work out what treatment you need or whether a treatment is working.

Scans are a bit like X-rays but can show much more detail, and usually take longer so you need to lie very still.

Here are some of the scans that you might need:

- MRI scan (magnetic resonance imaging) can show your whole body
- CT scan (computerised tomography scan) can also show your whole body
- Echo scans show your heart.

Find out more and check out the E-book 'my visit to the MRI scanner' on the Bristol Royal Hospital for Children's interactive website

Hello, my name is Sam and I've just had an MRI scan.
Let me tell you what happened…

Mum, dad and I had to go to the X-ray department. At the reception desk I had to tell them my name.

Welcome to the Network!

Meet Kindre

New ACHD Clinical Nurse Specialist in Cardiff

Where did you train?

I qualified as a nurse in 1992. I spent a year in neurosurgery and four years in medicine before I landed on the Coronary Care Unit in 1997. Since then I have worked in cardiology in both the University Hospital of Wales Cardiff (UHW), the Royal Glamorgan Hospital in Llantrisant, and as a Health Visitor in the Welsh Valleys. For the past five years I have worked on CCU and Pacing Theatre at UHW.

I joined the ACHD Clinical Nurse Specialist team in November 2020 and have spent the time so far getting to know the team, our patients (and their various and curious conditions) and the services provided in South Wales and the south west.

What are your interests?

I would like to help develop nurse led clinics in South Wales as part of phase 2, to support the medical staff, reduce travelling time for patients and help cut waiting times - especially in our post COVID-19 world.

I would also like to expand the services and support offered to women in the process of planning a family, women who are pregnant and new mothers with Congenital Heart Disease.

What about life outside of work?

Outside work I enjoy reading - Terry Pratchett is one of my favourite authors - and walking. I live close to the Welsh coastal path and love looking out to sea. When I can, I volunteer as a guide in the National Trust's Tredegar House in Newport.

I'm married and have two wonderful grown up children who both live in Wales and two cats!

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

Welcome to the network Dr Simon McDonald, new ACHD consultant in Cardiff, and Emma Benger, paediatric clinical nurse specialist in Cardiff.

Welcome also to Dr Muhammad Addin, Consultant Paediatrician with Expertise in Cardiology, at the Royal United Hospital in Bath.

Welcome to Joanne Holding, new paediatric service manager at the Royal Cornwall Hospital.. and Rachel Wyatt, new ACHD clinical nurse specialist at the Bristol Heart Institute.

Dr Francisco Gonzalez Barlatay has also been appointed as consultant cardiology interventionist at the Bristol Royal Hospital for Children in February 2021.

The Royal Cornwall Hospital is the first level 3 service to have their own Adult CHD Consultant Cardiologist

Introducing Dr Georgina Ooues

"I was delighted to be appointed as **a Consultant Cardiologist in Truro**, and I am really looking forward to making a contribution to the network"

"I completed **my training** at Queen Elizabeth Hospital in Birmingham and joined the team in Truro as an Adult Congenital Heart Disease Consultant (ACHD) in November 2020. **My special interests include** Adult Congenital Heart and Valve Disease, Transthoracic and Transoesophageal Echocardiography and Heart Disease in Pregnancy"

"In my spare time, I enjoy swimming and outdoor walks with my husband and young son. I am hoping to resume travelling around the world with my family once the COVID-19 pandemic is over and love reading books and solving crosswords"

"I realised early on in my training that **congenital heart disease excited me most** and wanted to contribute to the expert treatment these patients deserve closer to their homes."

"I am very excited to have moved to Cornwall, close to family, and becoming part of the Royal Cornwall Hospital Trust and the South Wales and South West Congenital Heart Disease Network. **In my new post, I aspire to provide high standards of care to the local population of Cornwall as well as further developing and improving the services."**

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

Network update

By Cat McElvaney, Congenital Heart Disease Network Manager, South Wales and South West

As we approach the end of the financial year (March 2021), our network members have been reflecting on the year that has passed, what has been achieved and the challenges our patients, families, staff and services have faced. Its a testament to the effort and commitment of our fantastic network members that despite the difficulties, they have continued to progress areas of work to benefit our CHD population, our staff and our services. For a flavour of what the network has been doing please see below;

Highlights – 2020/21

- ✓ **COVID-19 response**; Online resources for families and staff, national and network regular meetings for support and sharing information.
- ✓ **Significant investment** and increase in staffing for Adult CHD service in South Wales.
- ✓ **Improving advanced care** with the introduction of clinics in Bristol.
- ✓ **Going digital**; Virtual appointments, virtual board meetings, fetal webinars, virtual study days, educational & communication platform for our level 3 Paediatric Consultants.
- ✓ **CHD Nurse competencies** developed to support nurse training in our region.
- ✓ Enhanced **network performance reporting .**

Further detail on network achievements and challenges in 2020/2021 will in our Network Annual Report, due to be published soon.

Looking ahead, 2021-22

As a network we have been agreeing our priorities for 2021/2022. Restoration and recovery of our staff and services will be a key focus for the network. We are also excited to continue to build and expand our fantastic portfolio of education and training. This will include an excellent range of paediatric CHD nursing webinars, a study day for ECHO sonographers across the network, and psychological skills training for our clinicians. We will be working closely with our Welsh centres on adapting the CHD standards, and we will continue to develop clinical pathways and protocols to help ensure consistent high quality care for all our patients.

Our final workplan for 2021/2022 will be published in April on the network website. To keep up to date with network news and our publications please follow us on twitter https://twitter.com/chdnetworkswsw

NETWORK OBJECTIVES

- **To support the delivery of equitable, timely access for patients**
- **To support the education, training and development of the workforce within the network**
- **To support improvements in patients and family experience**
- **To be a central point of information and communication for network stakeholders**
- **To provide strategic direction for CHD care across South Wales and the South West**
- **To ensure it can demonstrate the value of the network and its activities**

Network Dates for your diary!

Key network meetings:

9 June 2021:

Clinical Governance Group (audit)

Network Board

16 September 2021

M&M
Network Board

Research in the network: Exercise prescription for young CHD patients

Recruitment of participants for the Heart Research UK (HRUK) funded study 'An evaluation of a physical activity and exercise promotion pathway for young people with congenital heart disease' has now started at the Bristol Royal Hospital for Children (BRHC).

The study is sponsored by the University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) and is in collaboration with the University of Exeter. Heart Research UK funding was awarded to Professor Graham Stuart, consultant cardiologist at UHBW and Professor Craig Williams, director of the Children's Health and Exercise Research Centre (CHERC) at the University of Exeter. Dr Lynsey Forsythe is a cardiac physiologist and senior research associate in cardiology and is leading the study at BRHC.

Physical activity plays an important and beneficial role in long-term cardiovascular and general health and whilst clinicians recognise the importance of promoting physical activity to young people with CHD, 'how' it is best promoted and delivered is not known.

The aim of this study is to evaluate the effectiveness of an individualised, six month physical activity and exercise prescription in young people with CHD by assessing changes in cardiovascular, physical and mental health.

Patient recruitment - Young people aged 12-18 years with a range of CHD are being recruited from BRHC cardiology clinics to participate in the six month, individualised, physical activity and exercise study. Participants entered into the study will be randomly allocated to an individualised exercise prescription or to normal care. The study will require extra visits by participants to the hospital for cardiac, physical and mental health assessments.

Results from the initial baseline assessment along with individual participant discussion will inform the type and intensity of physical activity and exercise prescribed for the six month period. Participants will have a choice of activities that are safe, appropriate and feasible for them to undertake, unsupervised at home.

Repeat assessments will take place at the hospital at three months and six months. Support will be provided to all participants throughout the study and any issues with the physical activity and exercise prescribed will be reviewed throughout.

The study follows on from the publication of a range of exercise toolkits by Heart Research UK promoting physical activity and exercise for people with CHD. The toolkits comprise a range of informative resources for patients and families, teachers and sports clubs. Access to these toolkits and further information can be found on the [Heart Research UK website]().

For further information regarding the study please contact Dr Lynsey Forsythe ([Lynsey.Forsythe@uhbw.nhs.uk]()).

For more information on research across the network and how to get involved, please see the research section on our [network website]().

Spotlight on audit!

Do you have a project in place or planned?
Or do you have a great idea that you would like support to take forward?
Or are you a willing volunteer in need of a good idea?

If your answer is yes to any of these questions then please get in touch with our network audit lead, Dr Helen Wallis
[Helen.Wallis@wales.nhs.uk]()

Network audits are presented at the network clinical governance group biannually – with the next one planned for June 2021.

Rowan's story

Shared by his mummy Kerry

When my son Rowan was one week old I noticed he looked a little blue around the edges, was breathing heavily and his fingernails had turned purple. We went straight to A&E in Bath because he was so young and small. My husband wasn't allowed to accompany us because of coronavirus restrictions.

When we got there it seemed like every screening test possible was performed on Rowan this was extremely traumatic for both him and me.

The test results kept coming back fine. It was great to hear that a lot of things had been ruled out but it was also worrying that something still wasn't right and we didn't know what.

The main concern was Rowan's oxygen levels. His oxygen levels were consistently around 80 and should have been in the high 90s to 100. For this reason, Rowan was given oxygen. It was thought that he had bronchiolitis but as time went on it became apparent this was not the case.

After a week in hospital being tested and given constant oxygen the doctors seemed really stumped. However, as one doctor thought he heard a heart murmur we transferred to the Bristol Royal Hospital for Children for an echocardiogram.

Diagnosis

The echo showed that Rowan had a displaced valve and a hole in his heart. This was why his saturation levels were low. It was reassuring to hear that Rowan's condition is on the mild end of the spectrum. However, he will need surgery later in life to fix the valve and to close the hole.

It was a very bitter sweet moment. After a week of worrying we had a diagnosis, but at the same time it wasn't easy to hear that our baby had something wrong with him.

The doctor explained that Rowan would need life-long monitoring but they were happy for him to go home. This was great news as I had been a week in hospital which meant a week of not seeing my husband or our two-year old!

Share your story

Do you or your loved one live with a congenital heart condition and would like to share your story?

We would love to hear from you.

We have a collection of stories on our website and also like to share patient stories anonymously at our network meetings.

Your stories help us to understand patient experience, and help us to improve and develop our services. They are valuable for learning and also celebrating success.

We would like to hear more about your experience of CHD care in South Wales and the South West.

Please visit the network website for more information or contact us if you would like to know more. We will always ask for your consent before posting on our website.

Rowan's story continued…

Going home

However, it was also daunting as Rowan had been monitored round the clock for a week and this would not be possible at home. I kept thinking "how do I know if he is getting enough oxygen or if his heart is okay?" My biggest fear was him going to sleep and not waking up.

The doctor then suggested that I stay in for another night so I could have a 'practice night'. They took Rowan off all monitoring so I could see what being at home would be like, without panicking or watching him all night long! This really gave me some peace of mind and reassurance.

I also took some photos and videos of Rowan where the doctors and nurses were happy that he looked well. If ever I doubt if he was okay I can look back at these pictures and videos for reassurance or to see if anything had changed for the worse.

The Future

We have had one appointment with the specialist who said they will look at surgery when Rowan is about seven years old. Rowan is currently being monitored every six months.

Here is a photo of Rowan at nine months old, doing wonderfully!

Rowan's heart condition is a rare condition called Ebstein's Anomaly. It is still very new to us and we have no idea how it will affect him as he grows older. Ebstein's Anomaly is usually picked up on at the 20-week scan. In Rowan's case this did not happen.

Looking back, when we took Rowan to A&E he was showing some of the five signs of Think Heart. I would like all new parents to be aware of these signs and not to be afraid to ask that their baby's heart is checked.

With Kerry's consent, Rowan's story was also shared at the network board meeting in March 2021 together with Kerry's suggestions on how she felt the network could help raise awareness. The board discussed learning from Kerry and Rowan's experience, and actions that could be taken. forward .

In Rowan's case ,his valve abnormality would have been very difficult to spot as it was on the milder end of the spectrum however the team are always keen to learn and improve practice so will be having teachings sessions delivered by the cardiac sonographers focusing on Ebsteins anomaly'. The board also had a good discussion around the 'Pulse Ox' study and which centres are using it as standard across the network.

The board would like to thank Kerry for sharing her experience as a way of supporting other families and driving improvements. .

Think HEART

CHF

When a baby is unwell think **HEART** to help spot the signs of an underlying heart condition. Early detection saves lives.

H	**Heart rate** Is it too fast or slow? (Normally 100-160 beats per minute)
E	**Energy** Is the baby sleepy, quiet, too tired to eat, falling asleep during feeds?
A	**Appearance** Is the baby pale, waxy, dusky or blue or grey in colour?
R	**Respiration** Is breathing too fast or slow? (Normally 40-60 breaths per minute)
T	**Temperature** Is the baby cold to touch, particularly hands and feet?

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.

Read all about it!

Heart Heroes and Heart Families South West have put together some heart-warming stories of hope to help support our CHD families – these are a collection of personal accounts written by heart families, and are available to purchase online at https://heartheroes.co.uk/shop.

Volume one is for under five year olds and volume two is for aged five plus year olds

Want to know more?

The network website is for patients, families and clinicians.

We have information on:

- Patient leaflets
- Getting support
- Hospitals & clinicians across the network
- Patient stories
- Patient pathways
- Clinical information
- Network meetings & 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 2021**, 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