South Wales and South West
Congenital Heart
Disease Network

Autumn 2020
Issue 8

Inside this issue

Newsletter

News from the network team

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

I hope this will inspire many of you to contribute to subsequent newsletter editions in the future. I particularly enjoyed reading "My Story with Congenital Heart Disease by Holly Jones" (page 14-15) which showcased how our various teams in Cardiff and Bristol worked in tandem to support Holly's recent surgical procedure and recovery. This culminated in her ability to climb a local mountain once again bringing back some childhood memories I am sure. Thank you to Holly for sharing your experience.

Whilst the pandemic continues to pervade all that surrounds us, it is gratifying to hear about teams adapting to new ways of working. Not least, the daily virtual meetings that are happening between our clinical nurse specialists in different hospitals. Digital teaching/training sessions continue to evolve particularly within our fetal cardiology service, with the development of a virtual roadshow and a programme of educational webinars.

There have been a number of staff changes recently in the network. I would like to welcome Dr Georgia Spentzou, a paediatric cardiologist with expertise in electrophysiology, to the Bristol team. I would also like to welcome back Dr Rowan Kerr-Liddell to Torbay from a period in Canada.

I am very excited to share the news that the Royal Cornwall Hospital has appointed Dr Georgina Ooues as a full time fully trained adult congenital heart disease (ACHD) consultant. This is a first for a district general hospital within our network and may be unique within the UK.

Another fantastic piece of news for CHD in our network is the confirmation that a significant investment has been secured in South Wales to support a major increase in ACHD service provision. More to follow as we recruit to these new posts!

Finally, I would like to congratulate Karen Sheehan on her work, particularly over the last 20 years firstly as a clinical nurse specialist and nurse educator, followed by her leading role within the CHD Research Department. After 37 years in the NHS, Karen retires very soon, though I am pleased that she will return to support the team on a part-time basis from January 2021.

Please keep safe during these difficult times.

Dr Andrew Tometzki

Funding approved to increase Adult CHD service provision in South Wales!

A business case to enhance ACHD services in South Wales was approved in August 2020 releasing c. £790k to improve CHD services in the area. This investment will significantly enhance the current service provision and will include an increase in the number of CHD consultants, nurse specialists, physiologist and psychology staff.

Meet Jess, one of our network lead nurses!

We are delighted to welcome Jess Hughes to the team as the new job share network lead nurse working with Sheena Vernon. Passionate about patient centred care, Jess was attracted to the role because of the focus on equality in healthcare. Jess has over 15 years' experience in paediatric nursing, mainly within cardiology. To find out more, check out Jess' profile on our network website.

Network Team Key Contacts

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COVID-19: new ways of working

Does the cloud have a silver lining?

By Lisa Patten, Paediatric Cardiac Nurse Specialist, Bristol Royal Hospital for Children

2020 has been a real year of change for us all. The COVID-19 pandemic has seen the clinical nurse specialist team working under significant pressures in an ever evolving healthcare environment; however, there have been many "silver linings" within these grey skies.

During the past few months, across the south wales and south west CHD network, the team have been pressed into new , innovative ways of communicating, one such way being virtual meetings with one another.

Being able to log into a meeting from every corner of the network has made Multidisciplinary Team Meeting (MDT) working a reality in a way that simply wasn't possible this time last year.

An MDT has traditionally been a face-to-face meeting of all professionals involved in the care of a patient in hospital. This includes cardiac nurse specialists, play specialists, psychologists. The rationale for this meeting is to ensure that every aspect of patient care is carefully considered and delivered to the highest standard by working together.

The cardiac nurse specialist teams, both at the Level 1 Centre (Bristol) and Level 2 Centre (Cardiff) have taken the opportunity to make the most of this "new" communication method on a weekly basis.

The teams have historically had daily contact with one another, ensuring excellent communication of patient/family care requirements during their transfer between centres; however, thoughts of their Welsh colleagues being able to join them for the weekly MDT had always been just out of reach – until now.

By utilising technology, the Level 1 clinical nurse specialists are delighted to be able to welcome the Level 2 (Cardiff) team to these meetings. There are many benefits to this - here are just a couple!

- The information exchange is instant, aiding continuity within patients' pathways, particularly at the point of admission and discharge/follow-up of complex patients.
- It is strengthening the working relationship between teams and enabling valuable (all be it virtual) face-to-face communication.

Technology is certainly bringing regional teams closer and this "COVID-19 innovation" is definitely one that the team intend to keep going forward.

Outpatients' goes digital!

With COVID-19 some outpatient appointments have been run using a virtual platform that enable patients to have an online consultation /video call with their consultant in a safe and secure way.

University Hospitals Bristol and Weston (UHBW) NHS Foundation Trust has been monitoring feedback from patients and staff to understand how well these online consultations are working.

In August over **860** outpatient appointments were held online, and for **71%** of patients this was the first time they had an appointment in this way.

85% of patients rated their appointment as good or excellent. It was a mixed picture when looking at preferences for video versus face to face with 39% saying they had no preference, 38% preferring face to face, and 19% favouring a video consultation.

Many of the positive comments included the hassle free nature of being able to have an appointment in the comfort of home, with no stress of parking and less risk of infection. Feedback also highlighted that this type of appointment works best for non-complex appointments that don't require a test.

It is clear that there is a place for online consultations in the NHS as long as it's for the right type of appointment and patient group.

For further information on virtual consultations at UHBW please visit:

http://www.uhbristol.nhs.uk/patients-and-visitors/videoclinics/

COVID-19: the impact on the CNS service in South Wales

By Bethan Shiers, ACHD Clinical Nurse Specialist

Similarly to the rest of the NHS; the impact of COVID-19 has had a significant impact on our ACHD service in South Wales. Patients were advised to contact their congenital centres for specific guidance on COVID-19/ACHD which meant our telephone calls, emails and texts increased exponentially.

With a current ACHD patient population of around 5,500 patients; running on skeletal staffing and with guidelines that were often changing, this was an extremely challenging time for our service.

Our weekly outpatient clinic appointments became 'virtual' rather than 'physical'. Patients in our cardiac centre (Cardiff) and peripheral hospitals were offered telephone consultations. We offered physical clinic slots for local symptomatic patients at the beginning of our weekly ACHD clinic at University Hospitals Wales.

We ran virtual 'transition clinics' for patients coming up to the adult service from paediatrics. Patients were posted individualised care plans and then the consultant and specialist nurse would go through this over the phone for further support.

We think virtual clinics are a positive way of working for some of our ACHD patients and are looking at offering this long term. We are also now planning to see patients who would like to be seen face to face again in clinic, with safety restrictions in place, provided COVID-19 numbers remain low.

We have been actively seeking community support to try and avoid patients coming into the hospital. Key multidisciplinary team work through liaising with district nurses, local centres, GPs, etc. have allowed us to successfully manage most of our patients at home. If patients were acutely unwell they were cared for within the hospital and we strived to ensure they could stay within a cubicle on a ward to try and minimise exposure.

As a nurse specialist I wanted to prioritise supporting our patients during this difficult time; therefore our audit work, education sessions and service development projects have been extremely limited. We are hoping to be able to expand on these when we are back to full staffing levels and are able to do so.

It has been a very surreal and challenging few months and I am hugely missing the patient facing aspects of my role. I am looking forward to slowly and safely reintroducing our full services bearing in mind that patient safety and support will always be our main priority.

Fontan clinics – coming in autumn 2020!

Nationally and internationally a number of centres are streamlining the way in which patients who have undergone a Fontan's procedure are cared for. This is something which is now being set up in the Bristol Heart Institute.

The aim of the clinic

The aim is to have both a cardiac and liver specialist present to assess the patient and co-ordinate the number of investigations which the patients require on a regular basis such as echocardiogram, cardiac MRI, CT, cardiac catheterisation and liver scan.

The clinic will ensure a co-ordinated approach between the two specialists and also in gathering results of a number of investigations which can be discussed in the multidisciplinary team meeting as required.

Clinic support

The clinic will be supported by the consultant cardiologist, the registrar, the adult congenital heart disease clinical nurse specialist and the Hepatology (Liver) team.

Guidelines

Guidelines on the management of patients who have had a Fontan procedure can be found in The European Society of Cardiology 2020 Adult Congenital Heart Disease (management of) guidelines. These will inform the assessing, planning and evaluating of patient care.

ESC
European Society
of Cardiology

Education and Training

Virtual Roadshow: Bristol fetal cardiology has launched a new virtual training initiative for obstetric sonographers across the region.

A pilot teaching session was launched in September to increase training opportunities and provide support for obstetric sonographers performing routine antenatal screening tests across the South West who refer into the Bristol fetal cardiology service.

Over the last 10 years there has been an increase in the training of sonographers, and this has resulted in a steady improvement in the rates of antenatal detection of congenital heart disease (CHD). However, despite an almost universal screening programme and a standardised approach to screening, detections rates still vary considerably across the UK.

Busy ultrasound departments with limited budgets often struggle to offer training opportunities, and these problems have recently been exacerbated due to the restrictions brought about by COVID-19.

The Bristol team, led by Consultant Paediatric and Fetal Cardiologist Dr Patricia Caldas, wanted to find alternative ways to provide sonographers with regular and easily accessible training opportunities which could be tailored to individual referring centers.

The first virtual teaching session was held on 15 September 2020 for the ultrasound department at Swindon's Great Western Hospital. Members were given a small presentation on the basics of fetal echocardiograms and one on transposition of the great arteries, with an overview of the fetal service and some tips on making appropriate referrals.

The future aim of this session is to give sonographers a regular opportunity for tailor made teaching sessions to suit their departmental needs, whether it is discussing recent cases, focusing on specific conditions or just an open questions and answers forum.

Sonographers are the key in improving detection rates of CHD. This new initiative is hoped to go some way to:

- Provide sonographers with a safe and inclusive platform to increase their knowledge and confidence in scanning the fetal heart
- Strengthen the network links between the Bristol fetal cardiology team and its referring centers.

2020 Advanced Symposium on Congenital Heart Disease in the Adult

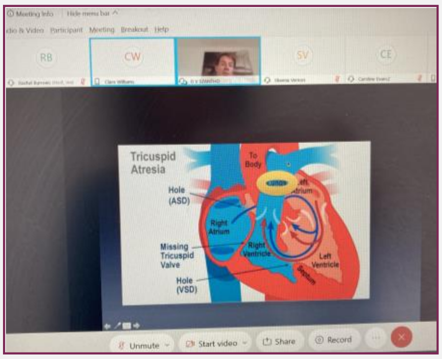
This national event was held virtually on 21 and 22 September. You can still access the recorded sessions and poster presentations by visiting https://achd.co.uk/

2020 Welsh Paediatric Cardiovascular Network Autumn education event

This regional event was held virtually on 17 September and was a great success, with a fantastic programme focusing on single ventricles and aortic stenosis. Thank you to all those involved! Watch this space for the next one in 2021!

2020 ACHD Virtual Study Day

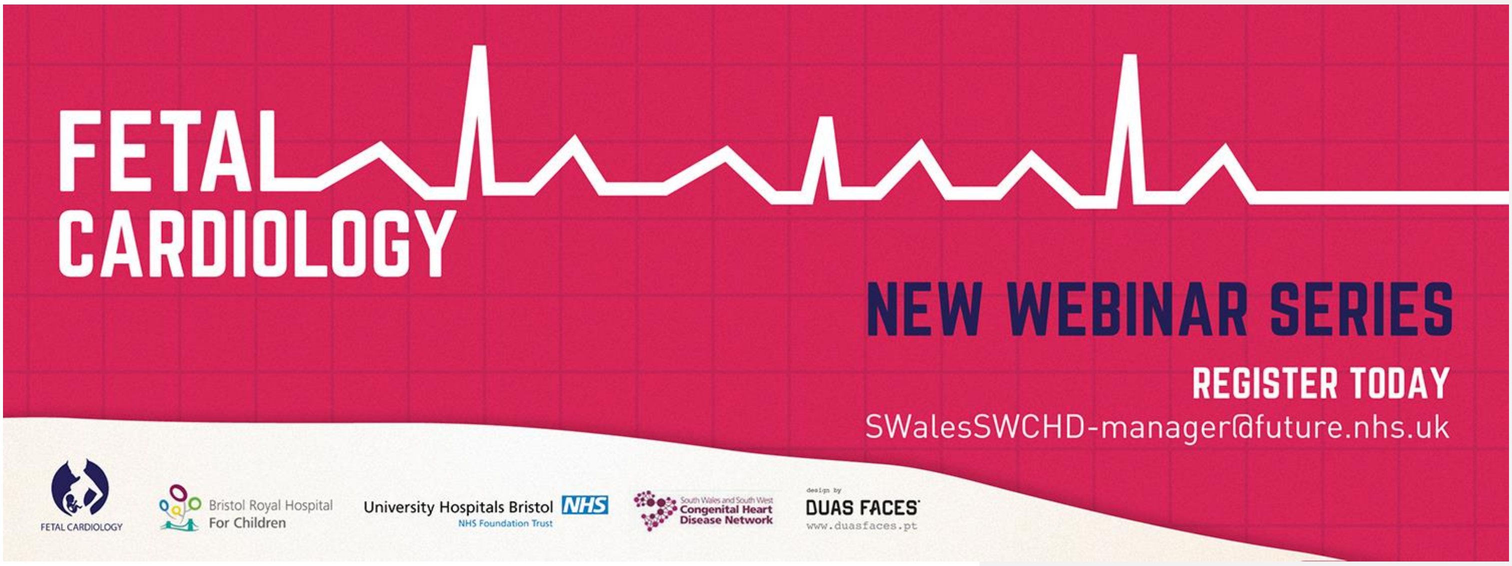
This regional education event held on 14 October was also a great success with over 85 delegates from across South Wales and the South West attending.



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
- Network psychology event, 2 February 2021 (virtual)



FETAL CARDIOLOGY

NEW WEBINAR SERIES

REGISTER TODAY

SWalesSWCHD-manager@future.nhs.uk

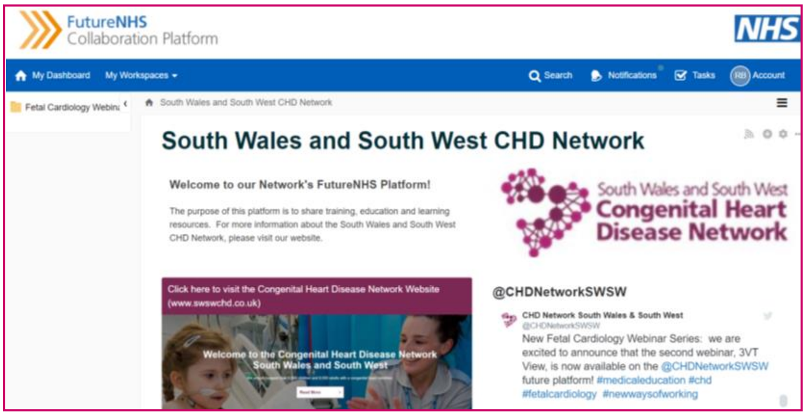
A new fetal cardiology educational webinar series was launched in August 2020 and is aimed at paediatric cardiologists, cardiac and obstetric sonographers, fetal medicine consultants, subspecialty trainees, paediatricians, neonatologists, radiologists, amongst others.

With 13 different sessions, this series covers a comprehensive and systematic approach to the normal fetal anatomy as well as the diagnosis of major cardiac abnormalities such as septal defects, left and right heart obstructive lesions and aortic arch abnormalities and transposition of the great arteries.

Alongside the webinars there will also be some echocardiogram quizzes with interesting and challenging cases.

During the webinars, health professionals can hear from Dr Patricia Caldas, Lead Consultant for the Fetal Cardiology Service and Paediatric Cardiology Department at the Bristol Royal Hospital for Children.

This series is hosted on the South Wales and South West CHD Network's new future platform! To register please email; SWalesSWCHD-manager@future.nhs.uk



South Wales and South West CHD Network

Welcome to our Network's FutureNHS Platform!

The purpose of this platform is to share training, education and learning resources. For more information about the South Wales and South West CHD Network, please visit our website.

Click here to visit the Congenital Heart Disease Network Website (www.swswchd.co.uk)

Welcome to the Congenital Heart Disease Network South Wales and South West

@CHDNetworkSWSW

CHD Network South Wales & South West
@CHDNetworkSWSW
New Fetal Cardiology Webinar Series: we are excited to announce that the second webinar, 3VT View, is now available on the @CHDNetworkSWSW future platform! #medicaleducation #chd #fetalcardiology #newwaysofworking

WEBINAR SESSIONS:

- Situs view and laterality disorders
- Three vessel and trachea (3VT) view
- Four chamber view, what is normal?
- Left ventricular outflow tract (LVOT) view
- Right ventricular outflow tract (RVOT) view
- Right aortic arch, double arch, head and neck vessels
- Tetralogy of Fallot
- Hypoplastic left heart syndrome (HLHS)
- Transposition of the great arteries
- Atrioventricular septal defects
- Ventricular imbalance and coarctation of the aorta
- Ventricular septal defects
- Rhythm assessment

Welcome back to the Network

Dr Rowan Kerr-Liddell

Consultant Paediatrician with Experitise in Cardiology returns to the Torbay team

I moved with my husband and two sons to Cape Breton Island, Nova Scotia on the east coast of Canada in the summer of 2017 after six happy years as a consultant paediatrician with expertise in cardiology and the child health clinical director at Torbay Hospital. We all wanted an adventure, to experience a different life and for me to be able to spend some more time with the family.

Cape Breton lies to the north of Nova Scotia, connected to the mainland by a causeway. It is at the same latitude as Northern Italy, without the gulf-stream effect the winters are indeed cold and snowy, but the summers are very hot and humid. It is a very beautiful island with the Bras D'or Lake forming a large part of the centre – the lake is 62 miles long and 31 miles wide – known as Canada's inland sea. To the north of the island are the Cape Breton Highlands with the scenic Cabot Trail winding its way around them on the coast.

The population of the island is very strongly Scottish in its heritage, there is a Gaelic college, multiple bagpipe bands and the amazing Celtic Colours Festival takes place in the autumn with international musicians gathering to hold ceilidhs and concerts. There is also a large indigenous population from the Mi'kmaq population, many of whom spoke English as their second language.

There are 4 paediatricians on the island, covering an area of nearly 4,000 square miles, with a population of around 160,000. Our nearest children's hospital was in Halifax, 260 miles or 4 ½ hour drive away. It was certainly a different experience for me and I loved it!

We had an amazing time as a family, swimming, hiking and exploring in the summer, and in the winter making the most of a small ski hill nearby which was a real luxury.

There are lots of things I will miss about living and working in Canada, but Torbay is home and it's good to be back. I am looking forward to seeing how all the cardiac children have grown and developed in the last 3 years, renewing old friendships and making new ones.

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

Welcome to Georgia Spentzou, EP consultant, who joined the Bristol Royal Hospital for Children (BRHC) in September 2020, and also to Daniel Meiring, cardiac physiology service manager who joined the team in June 2020.

Welcome also to Llinos Griffith, specialist paediatric cardiac psychologist, who has joined the Cardiff and Vale team, and to Hannah Mustard at the Bristol Heart Institute (BHI) who is temporarily covering Michelle O'Keeffe whilst she is on leave.

The network is looking forward to welcoming Dr Georgina Ooues to the network in November 2020, as the new ACHD Consultant Cardiologist at the Royal Cornwall Hospital.

Dr Greg Szantho, consultant cardiologist, (pictured below) moved from Cardiff in October 2020 to join the Bristol Heart Institute.

The BHI is also pleased to welcome two new Clinical Fellows, Dr Ordonez and Dr Mansour.

We are sad to say goodbye to Di Addington, Service Manager covering the ACHD service at North Devon NHS Trust. We welcome Dan Smith who took over this role in October 2020.

The BRHC cardiac research team have bid a fond farewell to Nicola and Kathy, and are pleased to welcome Gemma Dibble and Kelly Saunders to the team. Both are experienced nurses from Dolphin ward. Karen Sheehan is due to retire in November 2020 and is returning to manage the team on a part time basis in January 2021.

Cardiac Scientist Clinic Programme at the Royal Cornwall Hospital

The Royal Cornwall Hospital NHS Trust (RCHT) has been successful in employing a cardiac physiologist and is initiating a **cardiac scientist led clinic programme** to support the Paediatricians with Expertise in Cardiology (PEC) and also improve the service for patients.

The RCHT is delighted to welcome Gemma, who has worked in adult cardiology for a number of years, to their team. Gemma has already been a regular feature in the congenital clinics and has recently been successful in obtaining her EACVI accreditation for congenital heart disease earlier this year.

Gemma is to work with RCHT for 2 days a week initially in a variety of roles:

- **Developing new patient pathways** such as the Outpatient Cardiac Scientist led clinic, and enhance the inpatient echo service for paediatrics and neonates
- **Supporting the PEC clinics** (and potentially the joint cardiac clinics) to increase the number of patients the team are able to assess
- Attending the department meetings to **improve the echo peer review** process and also join the tertiary joint cardiac conference
- Actively **contribute to the cardiac department audits**, database initiatives and other projects within the team.

Benefits of the outpatient cardiac scientist led clinical programme are expected to include:

- ✓ Reduction in waiting times
- ✓ Utilising time better in face to face clinics
- ✓ Combining clinician assessment (over the telephone in some circumstances) with later access to an echocardiography assessment
- ✓ Improve patient experience
- ✓ Enhance the continuing professional development of the team.

New equipment for the cardiac physiology department at the Bristol Royal Hospital of Children

With thanks to the Grand Appeal (hospital charity), a new bicycle ergometer (exercise bike) is now being used by the cardiac physiology department at Bristol Royal Hospital for Children to help assess their patients.

Before the bicycle was installed, the department had relied on a single treadmill to perform assessments which was not always appropriate for all patients.

The bicycle will also aid ongoing and future research studies performed by the cardiology department.

Michelle Crockett, play therapist on Dolphin Ward at the Bristol Royal Hospital for Children has recently come second in the

National 2020 Starlight Health Play Specialist of the Year Awards

Well done to Michelle on this fantastic achievement!

Fetal Cardiology in Bristol

Congenital heart diseases (CHD) are one of the most common birth defects, affecting 8 in 1000 new born babies every year in the UK.

Fetal cardiology is a subspecialty within the Paediatric Cardiology field, which aims to diagnose this disease antenatally.

The concept of prenatal screening for CHD was introduced in the UK over 20 years ago and current national guidelines recommend that the heart should be examined at the time of the routine pregnancy scan. When a cardiac condition in the fetus is detected during standard assessments, a fetal echocardiogram will be performed.

The Fetal Cardiology Department in Bristol receives approximately 1000 referrals per year and around 200 cardiac conditions are diagnosed. Some of the initial referrals are linked to patients with family history of CHD, abnormal rhythms, pathologies detected in the fetus in other systems or association of certain medication in the pregnant woman with cardiac anomalies.

The most common CHDs identified are:

- Hypoplastic Left Heart Syndrome
- Atrioventricular Septal Defects
- Transposition of the Great Arteries
- Tetralogy of Fallot.

Although the heart is already beating 4 weeks after the moment of conception, the position of the baby in the womb and the small size of the cardiac structures can make it difficult to visualize important parts of it, such as the vessels coming out of the heart, which are of major importance.

To improve the accuracy of the diagnosis, the Fetal Cardiology team is aiming to start developing a Fetal Cardiac MRI program together with 3D cardiac ultrasound.

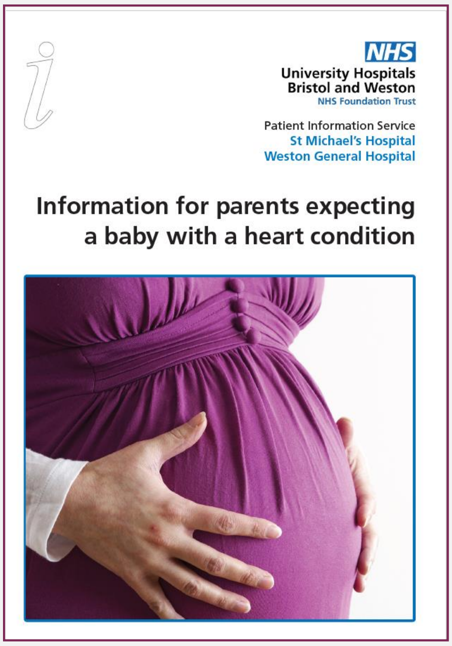
Fetal Cardiac MRI mainly helps to see the great arteries (the vessels coming out of the heart). The combination of both techniques will help to improve the precision of the antenatal diagnosis, contributing to plan the management of the babies after birth.

A new fetal cardiology fellow, Mari Nieves Velasco, is starting in November 2020 and will help in the development of both techniques. She will act as a link between the department at the Evelina London Children's Hospital and Bristol, importing the knowledge from these emerging advanced imaging methods into the diagnostic pathway.

To find out more, email Dr Velasco on mnieves.velasco@kcl.ac.uk

To find out more about the **Fetal Pathway** please visit our network website.

The recently updated **information leaflet** (below) provides information on who the fetal cardiology team are and what their involvement will be during the antenatal journey – this can also be found on the network website



NHS
University Hospitals
Bristol and Weston
NHS Foundation Trust

Patient Information Service
St Michael's Hospital
Weston General Hospital

Information for parents expecting a baby with a heart condition

Useful patient support websites include:

Little Hearts Matter www.lhm.org.uk/

Tiny Tickers www.tinytickers.org/

Children's Heart Federation www.chfed.org.uk/

ARC www.arc-uk.org/

Antenatal Results and Choices

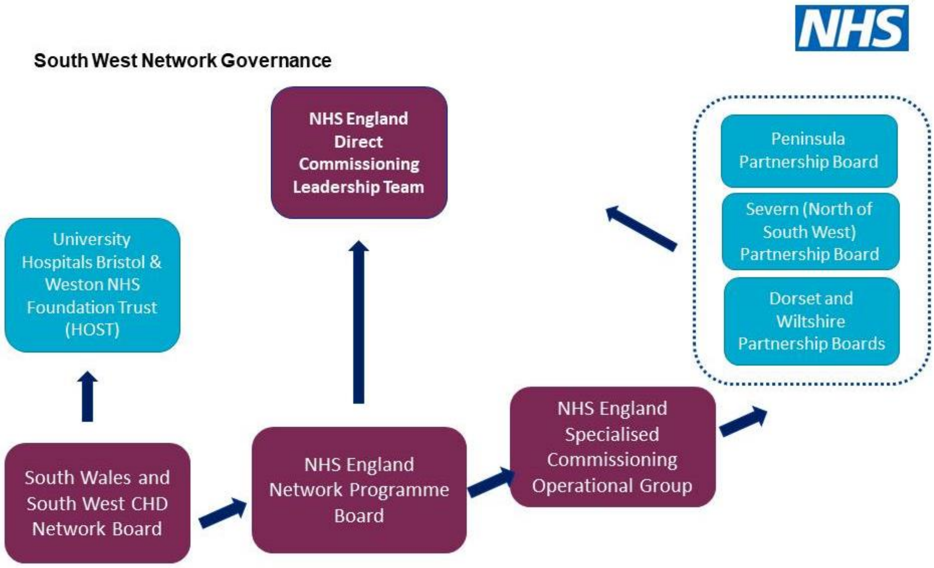
Network Governance update

The CHD Network is part of a group of seven operational delivery networks in the South West that are funded and report into NHS England. These networks have been set up to help coordinate care pathways across hospitals to ensure patients have consistent, equitable access to specialist resources and experiences within their clinical area across the region.

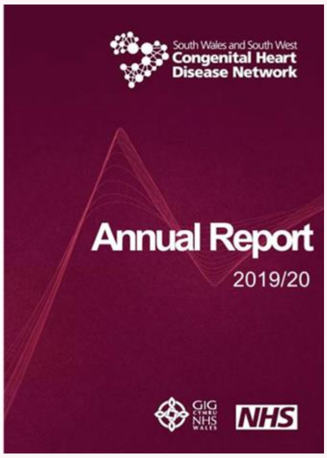
The CHD network brings together clinicians, managers, patient/family representatives and commissioners across South Wales and the South West to work together supporting patients with congenital and paediatric acquired heart disease and their families.

Recently, a **Memorandum of Understanding** has been drafted by NHS England that describes the role and purpose of networks, and the expectations on organisations that form part of it. This enables all parties involved to be clear on what their role is, and it shows a clear commitment of those signed up, to work together to ensure safe and effective services for patients and their families.

The **governance structure** of the CHD network is illustrated below. On a quarterly basis the network reports into both NHS England (Network Programme Board) and University Hospitals Bristol and Weston NHS Foundation Trust (UHBW). This includes updating on progress against the networks workplan and escalation of any risks or issues arising within the network.



CHD Network in 2019/2020 – Read all about it!



The Congenital Heart Disease Network Annual report for 2019/20 has just been published!

Find out about the key achievements and challenges for the network in its fourth 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 to read it in full.

Network Dates for your diary!

Key Network Meetings:

10 November 2020:

Network priorities 2021/22 planning session

8 December 2020:

Network Board & Clinical Governance Group

9 March 2021:

Network Board & Clinical Governance Group

Cardiac Physiotherapy

By John Stiven, paediatric physiotherapist

Paediatric physiotherapists are an integral part of the cardiac multidisciplinary team at the Bristol Royal Hospital for Children.

Physiotherapists will be involved in the child's journey from day 1 on the Paediatric Intensive Care Unit (PICU), to helping prepare patients for discharge home.

Highly trained paediatric physiotherapists provide respiratory care, promote early mobilisation and meet specific rehabilitation needs. Physiotherapy is available 24/7, 365 days a year when necessary.

A common complication following cardiac surgery is a temporary reduction in mobility. In the more complex surgeries, prolonged bedrest and reduced exercise tolerance can limit a child's opportunities to meet their developmental milestones. Timely intervention is vital to facilitate normal development and promote recovery.

Recently, the physiotherapy team has put together a "getting you home faster" tool for the Cardiac (Dolphin) Ward, which offers basic advice to promote lung health, and gives simple goals to help achieve early mobilisation. These laminated, reusable forms are available on the ward to assist staff, parents and patients.

The physiotherapy team is also working with the PICU consultants to develop an early mobilisation programme, called "EPIC" (Early mobilisation on Paediatric Intensive Care). This programme will assign patients into one of three categories based on their medical stability and requirements (red, amber or green). Each category has predetermined activities that can be selected for the individual patient.

This promotion of early mobility has the potential to:

- ✓ Prevent problems associated with their PICU stay
- ✓ Expedite return of normal function
- ✓ Improve patient flow.
- ✓ Improve patient outcomes
- ✓ Provide many #epicmoments!

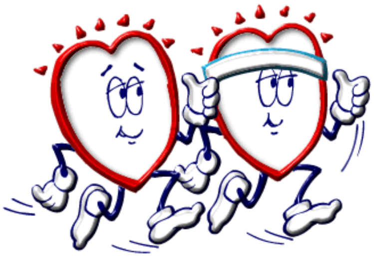
The paediatric physiotherapy team are constantly reviewing the treatment provided and developing new and innovative interventions. In addition to the above, our future plans include preoperative assessment to promote normal development and to identify or predict any rehabilitation needs prior to surgery.

New guidelines on sports cardiology for CHD patients

The European Society of Cardiology has published two new academic papers on sport and exercise advice for congenital heart patients:

- ✓ 2020 Guidelines on sports cardiology and exercise in patients with cardiovascular disease.
- ✓ Recommendations for participation in competitive sport in adolescent and adult athletes with Congenital Heart Disease (CHD).

Visit the European Society of Cardiology website to find out more.



Exercise prescription in children

Professor Graham Stuart, Consultant Cardiologist at University Hospitals Bristol and Weston, is working with recently appointed Dr Lynsey Forsyth PhD on a new 2 year project.

This project will be evaluating exercise prescription in children aged 13 to 18 years with congenital heart disease.

Did you know…?

Professor Graham Stuart was appointed Honorary Associate Professor of Sports and Exercise Cardiology, University of Bristol in 2018.

Professor Guido Pieles, Consultant Cardiologist at University Hospitals Bristol and Weston, was appointed Honorary Associate Professor in Sports Cardiology, University of London in 2020.

Research in the network

By Karen Sheehan, Research Nurse, Bristol Royal Hospital for Children

The paediatric team at Bristol Royal Hospital for Children has continued being research-active during the pandemic and used their skills to help with vaccinating patients in the Oxford vaccine study.

Over the summer when lockdown eased, the research team was busy looking at the practicalities of restarting other studies and opening new studies.

OMCp

The OMACp (Outcome Monitoring after Cardiac procedures in children and young people) study has continued to recruit throughout COVID-19 and recently reached 500 recruited patients! The study aims to collect clinical information and samples (blood, urine and tissue) to facilitate future research into how we care for cardiac children and young people.

Currently the following studies have recommenced:

PEACOCK aims to study the stress response to cardiac surgery and cardiac catheterisation in children and babies. This is done by inserting a fine catheter under the skin in the abdomen when the child is asleep and draws off fluid from the tissue every 10 minutes for up to 24 hours. Prior to this ground-breaking technique, little was known about the impact of cortisol (the stress hormone) in children as they were only able to get 6-7 serial blood tests. Now they can get up to 144 consecutive samples

MEDLEY is a clinical study researching a medication for cardiac babies at high risk for respiratory syncytial virus (RSV) disease. The study is looking to see if it works as well as another medication. If it is successful, the new medication would mean one injection would be given instead of four during the RSV season.

The research team has also been able to finish setting up a post-market registry for Cardiocel, Cardiocel neo and Cardiocel 3D. These are products which are used during cardiac surgery to, for instance, close VSDs. Bristol was the first site opened in the UK and has already started recruiting patients. Mr Stoica, Consultant Surgeon at the Bristol Royal Hospital for Children, is the Principle Investigator for the study in Bristol and he hopes to open up the registry in the Bristol Heart Institute as well.

Other work has been ongoing for studies which had completed recruitment.

THERMIC 3 - The recruitment for this study has completed. This study is looking at whether it is better to use cold or warm medicine to stop the heart during cardiac surgery in children and young people. The team look forward to sharing the results soon!

CARDIOMAN is a medicine study for patients with BARTH syndrome. The study has completed all patient visits and the team are busy sorting out data to assess if the medicine helped or not.

THANK YOU

Thank you to everyone who has engaged with research during their stay at the Bristol Royal Hospital for Children, whether or not you were able to take part. These studies would not be able to run without the support of our patients and families.

For more information on research across the network and how to get involved, please see the research section on our website:

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

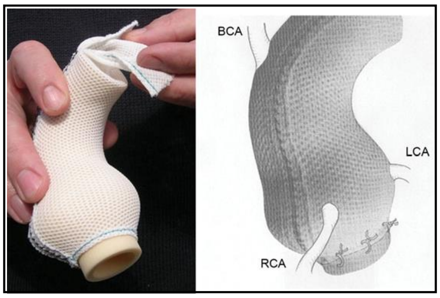
Personalised External Aortic Root Support (PEARS)

By Shafi Mussa, Consultant Congenital Cardiac Surgeon, University Hospitals Bristol and Weston NHS Foundation Trust

Patients with conditions that affect the strength of their connective tissue (connective tissue disorders such as Marfan's Syndrome) can have multiple medical problems. One particular issue is abnormal enlargement of the aorta (the major blood vessel that leaves the heart and supplies blood to all parts of the body). As the aorta continues to enlarge there is more stress on its wall, which can eventually split. This condition is called aortic dissection, and is a catastrophic life-threatening event. It has a high death rate, and requires high-risk emergency surgery to save the patient's life.

Cardiac surgeons have developed operations to replace the aorta as it leaves the heart, with a view to preventing aortic dissection and the complications that may arise if it occurs. These major operations involve either replacing the aortic valve as well as the aorta (aortic root replacement), or replacing the aorta only and leaving the patient's aortic valve in its natural position (valve sparing root replacement). Currently, the available evidence supports valve sparing root replacement as the treatment of choice for patients with aortas that are over a certain size, or are expanding too quickly over time. This procedure is performed by the congenital cardiac surgeons in Bristol, and is offered to patients within the Network.

Over the last 15 years, Personalised External Aortic Root Support (PEARS) has been developed as an innovative surgical treatment for this condition, and is an alternative to valve sparing root replacement or aortic root replacement in specific situations. It involves placing a specifically manufactured mesh sleeve around the aorta as it exits the heart, which prevents further enlargement of the aorta and theoretically reduces the risk of aortic dissection.



Patients who may benefit from and agree to proceed with this procedure need to have a specific scan to provide measurements for the design and manufacture of a sleeve which is unique to their aorta. The operation to implant the sleeve around the aorta is undertaken through a cut down the breastbone similar to most heart surgery, but importantly does not usually require the use of a heart-lung machine, or involve stopping the heart. It is a shorter operation than either valve sparing root replacement or aortic root replacement.

317 of these operations have been carried out worldwide to date, with a survival rate of over 99%. Currently the procedure is being offered in 7 centres in the United Kingdom, including Bristol. The operations are being performed by the surgeons in Bristol with proctorship and support from a surgeon in London who has the world's largest experience. If the short-term success translates into similar medium and long-term success then this procedure may become the treatment of choice to prevent aortic dissection in patients with connective tissue disorders and other congenital aortic diseases.

The surgical pathway tells patients more about:

- What happens when they have cardiac surgery
- The team may first talk to the patient about this in their local clinic
- And then refer the patient to The Bristol Heart Institute, which is the specialist centre for adult congenital cardiac surgery in South Wales and the South West.

Check out the adult surgical pathway on the [network website]

Preparing for surgery

Where can I get support?

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

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

Bristol Heart Institute

Virtual Tour

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

A further impact of COVID-19 has been the suspension of young people's 'open evenings' at the Bristol Heart Institute.

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 see 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 adult congenital heart disease clinical nurse specialist team has been working on producing a film which can represent the evening. The film will have an overview of the Bristol Heart Institute and a commentary to describe the clinical areas. There will be a section about the team and what it will be like for patients coming to the hospital.

This film will be available to all those young people who may be seen in peripheral clinics around 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.

The film will be posted on the trust and the network websites, so watch this space!

Introducing Monet

New Community Youth and Family Worker

Welcome to Monet

With support from The National Lottery, Youth@Heart, a charity that supports young people aged 15-24 (and their families) across the network, has recently employed a Community Youth and Family Worker, Monet Williams.

Monet offers additional support to our patients and their families, as our young people move in and out of hospital. She will also be the charity's voice in the community.

Xander

Xander Cook, ACHD Youth Worker, continues to support our young people in the Bristol Heart Institute as in-patients and via text and telephone. Face to face opportunities in the outpatient setting have been limited due to COVID-19.

Find out more on the network website and at http://www.youthatheart.co.uk

My story with Congenital Heart Disease

By Holly Jones

At the age of 8 I kept getting chest infections and my GP then found a heart murmur. I was then referred for chest x rays and an echocardiogram where I was then diagnosed with aortic stenosis and a bicuspid aortic valve which was caused by congenital heart disease. I spent 21 years of my life being restricted in the activities I could do and being closely monitored by the cardiology team at the University Hospital of Wales. Having said that, it did not stop me living the life of a normal person! Throughout these years, I developed health anxiety mostly relating to my heart problems, this caused me distress for many years, and I was forever worried that the worst would happen. My team at the Cardiology Unit has always been so supportive and they have always been accessible to me.

When I was 17 years of age, I transitioned from paediatric to adult care with the support of the GUCH (Grown Up Congenital Heart) nurses. I signed up to the GUCH newsletters which helped me tremendously to read people's positive stories.

As the years went by, my care was taken over by the ACHD (Adult Congenital Heart Disease) team and my ACHD nurses Sarah Finch and Bethan Shiers. I can honestly say that these nurses, together with consultant cardiologists Dr Wilson, Dr Masani and Dr Szantho have been amazing. The whole team are just the best!

In June 2018, I was put on a treadmill test and after the results of this, it was decided that it was time for me to have my valve replaced. I was referred to the surgeon Dr Stoica at Bristol Heart Institute. I was invited to meet Dr Stoica in December 2018 along with my family so that we could discuss my options. I was lucky enough to be given the option of having the Ross Procedure which would be done by a specialist surgeon in Bristol Heart Institute. I choose this option as it gives me the best chance of living a normal life. There had to be back up plans which included a bovine valve and at last resort a mechanical valve.

During the time I was on the waiting list for the surgery, I was referred to Michelle O'Keefe who is the cardiac Psychologist at Bristol Heart Institute. **Michelle provided therapy over the phone and was a much-needed resource for me on the lead up to surgery and I highly recommend that anyone who is anxious around having heart surgery asks to be referred for counselling.**

In June 2019 I had to attend my pre-op assessment at Bristol Heart Institute where I was greeted by the ACHD Nurse Caryl Evans. Caryl could tell how anxious I was and had been talking with Beth and Sarah from the Cardiff Team and was aware of my health anxiety. Caryl made everything so much easier to comprehend.

I finally received the date for surgery, 20 August 2020 at the age of 29. This worried me tremendously and seeing the looks on the faces of my family, especially my parents on seeing it in writing was heart-breaking, but we all prepared together as a family.

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 follow this share your story link 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.

On the morning of the operation, there was a delay with the surgery as there had been an emergency. I was so scared. In my mind there was no way I was going through with this surgery, Cheryl, a lovely healthcare assistant, and Caryl (ACHD nurse) tried to reassure me along with the surgeon Dr Stoica. During the 7 hours I was in theatre my family waited anxiously in the hospital café, Dr Stoica then went to tell them that the operation had gone well and that I was in recovery but I was not out of the woods until I woke up.

At 12am I woke, I remember I was trying to talk so the nurse came and I had to cough out the tube from my throat and I just remember thinking, I'm alive! At 6am the nurse came to take my drains out and it wasn't as bad as I was expecting. Following CICU (cardiac intensive care unit), I was moved into the high dependency section of the ward. I was so happy to see my family.

I had a few complications when I was in hospital and was in high dependency for 10 days. During this time, I was always anxious about what was going wrong and the team at BHI was absolutely outstanding. My surgeon came to visit and told me that the operation had gone just as he had planned and told me that the complications were very common and that they could be sorted out. Caryl (ACHD nurse) and Pol (nurse practitioner) were so supportive and encouraging.

Every day was an improvement. I met small milestones like walking for the first time, and showering etc. It was really reassuring that everyone was telling me how well I was doing despite the complications.

On day 10 I was moved to the ward, still unable to go home due to the fluid around my heart and chest infection. I settled in and began to walk up and down the corridors and meet people. On day 14 I was able to go home. I cried once I sat down in the chair at home, I was so thankful and so overwhelmed to actually be home and that the operation was done.

I couldn't move much for the first 8 weeks, so my family waited on me hand and foot, and helped me build my strength again. Without my family I could not have done any of it, I will forever be grateful.

9 weeks post op I was admitted into the University Hospital of Wales as I had a lung infection and pericarditis. Beth, Sarah, Dr Szantho and Dr Masani gave me such excellent care and made sure that I knew I was going to be ok. I was in for 3 nights and then they discharged me and I had to return for regular scans in outpatients.

During my recovery time I had pericarditis numerous times and this set me back but I returned to work in February 2020 and in July 2020 I finally completed my Cardiac Rehab programme (remotely due to COVID-19).

In August 2020, I celebrated my 1 year valversary by climbing my local table top mountain, which I haven't done since I was 8 years old!

I will continue to have regular check-ups for the rest of my life and I believe that I have the best team looking after me.

My scar is healing lovely too (see photo to the left) and I am very proud of it!

Supporting patients & families in this new world

Psychology Support

A virtual psychology service is now on offer, so patients can join via video or telephone. Alternatively, the team can meet patients if they prefer to come into hospital or are an inpatient on their site.

New webinar series!

The team are also introducing some new webinars to help support patients and families, which will include:

- Coming into hospital
- Preparing for surgery
- Supporting siblings
- Managing stress

What are webinars?

Webinars are short sessions via an online link that families can access. There will also be Q&A sessions for general questions. Watch this space for more details!

Any ideas?

We would love to hear your ideas on other topics for future webinars – please email your ideas to: Vanessa.Garratt@uhbw.nhs.uk

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.

This current time has highlighted how support is very much needed. The purpose of the Heart Heroes HUB is to extend Heart Heroes' reach and support for children and families living with heart conditions through social events.

Heart Heroes Founder Kelly Cornish has shared that "our goal is for children and their siblings to be included in all our events, along with parents, grandparents, aunties, uncles and any other close family. By opening two new centres, we can reach more families. When we are allowed to meet up again, we will start putting on local events for them, which will include coffee mornings where parents meet and support each other."

For more information on the Heart Heroes HUBs visit www.heartheroes.co.uk.

Cardiac Pre-Admission Postcards

The Bristol Royal Hospital for Children cardiology team and the Grand Appeal charity have designed and funded new 'Cardiac Pre-Admission Postcards.'

The cards will help practitioners to understand which investigations have taken place and which are still outstanding for that patient.

The postcards are also a fun and easy way for children to document their treatment, helping to ease anxiety while providing parents with clear information around their child's care.

For further information contact either Beth Brock, Cardiac Clinical Nurse Specialist, or The Grand Appeal at: hello@grandappeal.org.uk

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.

Find us online:
www.swswchd.co.uk
Tweet @CHDNetworkSWSW

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Thank you for reading!

If you have any stories or ideas you would like to share for the next edition in **Spring 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. If you would like to sign up to our mailing list, please email Rachel Burrows, network support manager on the address above or you can sign-up on the home page of the network website:

www.swswchd.co.uk