

# Newsletter

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## News from the network team

Welcome to our spring edition of the South Wales and South West Congenital Heart Disease Network newsletter! Published a little later than planned due to Covid-19 hitting us, but as always it's full of interesting updates on what our patients, families, clinicians and charities have been doing across the network; helpful articles on key services for congenital heart disease; and signposting to a number of important network meetings, as well as training and education events.

Little did we realise that 2020 would see the world face one of the greatest challenges of modern times with the Covid-19 pandemic. Whilst the last few months have presented many challenges, particularly for our clinical staff, there have also been a lot of positives. This time has focussed society's hearts and minds on what really matters at times like this; the care and support of our loved ones, our communities and our key workers. Each Thursday, the nation has clapped to show their appreciation and thanks to all of the wonderful people who have made personal sacrifices to care and help people out in a time of need.

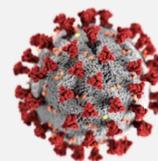
In response to Covid-19, people have adapted with new ways of working. Whilst some of these changes in ways of working will be temporary, there will undoubtedly be things people will want to retain. We would love to hear about these, share the learning across the network and support you to carry these on. Please [email us](#) to tell us about them.

In 2019, the World Health Organisation (WHO) designated 2020 as the year of the nurse and the midwife; celebration and recognition of the pivotal role nurses and midwives play in society. We talk about the how the NHS plans to mark this occasion and highlight some of the fantastic work of nurses within our own network. We also pay tribute to Wendy Visser, one of our wonderful Adult Congenital Heart Disease nurses who sadly passed away towards the end of last year. There is also an update from Sheena Vernon, our lead nurse for the network, on progress with growing the population of link nurses, who play an important role in supporting our CHD patients and their families across the network.

A key focus over the next few months for the network will be to support staff and services as they begin to restore routine CHD activity. The quarterly network board will go ahead in June virtually. This will provide a good opportunity to reflect on what has happened, and also to review and agree the network priorities for 2020. Watch this space for further details!

Finally, a big thank you to everyone who has contributed to this newsletter. It's lovely to share your stories and updates with others across the network. We hope you enjoy the read!

## Coronavirus (Covid-19)



**We appreciate that this is an unprecedented and uncertain time for so many, but we will get through this together #StaySafe**

To support our CHD staff, patients and families across the network, we have set up Covid-19 webpages ([www.swswhd.co.uk](http://www.swswhd.co.uk)) with recent guidance and information. Importantly, it also has a wealth of wellbeing resources that may help you navigate this challenging time. We will continue to update these pages with helpful information as we receive it.

The UK government have issued guidance on social distancing/self-isolation for many vulnerable patient groups, including those with long-term health conditions. The BCCA would encourage patients to check this guidance which may change during the course of the Covid-19 pandemic.

For guidance regarding operational delivery during this time, please visit your local hospital's website.

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### Network Team Key Contacts

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# International Year of the Nurse and Midwife 2020

**What is this and why 2020?** The World Health Organisation has dedicated 2020 as the first ever international year of the nurse and midwife, with the aim of raising the profile and celebrating the expertise and diverse talent of both professions. This coincides with the 200<sup>th</sup> anniversary of the birth of nursing pioneer Florence Nightingale.

2020 has certainly highlighted the absolute pivotal role nurses and midwives have in delivering care for the nation and looking after loved ones. Since the start of the Covid-19 pandemic in the UK and across the world, there has been a resounding call out of thanks and gratitude for our key workers, including our nurses and midwives. There has been worldwide recognition of the dedication, commitment and personal sacrifice they are making to look after us all during this difficult time.

**Get involved:** Throughout much of the year, events and activities are being planned across the UK to celebrate the professions. At University Hospitals Bristol and Weston, the hospital will be working with local partners to celebrate with colleagues and the community. Celebrations will now take more of a remote or digital form, but we will continue to recognise and thank nurses and midwives across our networks.

## People stories for nurses and midwives – we would love to hear your story!

Over the year, NHS England is gathering people stories and as a Network we would also like to share any related to CHD at our stakeholder day. If you would like to share your story, please do email us and let us know – [rachel.burrows2@uhbw.nhs.uk](mailto:rachel.burrows2@uhbw.nhs.uk).

We'll send you a template to complete or alternatively visit

<https://www.england.nhs.uk/year-of-the-nurse-and-midwife-2020/people-stories/>



*Thank you!* 

**As a Network team, we would like to take this opportunity to recognise and celebrate the enormous contribution by our nursing teams in the care of patients of all ages with congenital heart disease and in the support of their families.**

## Here's Beth Brock's story



I joined the Bristol paediatric cardiac nurse specialist team in November 2019. Prior to this, I had been a staff nurse on Dolphin Ward, Bristol Royal Hospital for Children (previously known as ward 32/Cardiac) for just over four years, and loved being part of such an amazing, supportive team.

This was after having completed my BSc (Hons) degree in Paediatric Nursing at the University of the West of England. Whilst in Bristol, I met my husband, Jamie. We now have a daughter who is nearly 2 years old, and is turning into a hilarious, wild little girl!

# Link Nurse/CHD Nurse Role

By **Sheena Vernon**, network lead nurse

We are excited to see the development of the **link nurse/CHD nurse role** within the network and we are very grateful to those nurses who are developing this part of their service locally. As we repeat the self-assessment visits to all of the level 3 centers it has been encouraging to discuss the role with the matron and senior nurses in the meetings.

The aim of the CHD nurse is to **provide a sign-posting role** for patients and families, to **provide support** to patients attending out-patient clinics and also to any in-patients and their families, and over time be able to provide telephone and email support.

## Orientation

It is hoped that during 2020, nurses that are unfamiliar with the way our level 1 centre (Bristol) works will be able to come to Bristol for a two day orientation to understand the workings of the joint cardiac conference, the ward rounds and outpatient clinics. These visits will be supported by the congenital clinical nurse specialist teams. The clinical nurse specialist teams will be available to support the link nurses with any specialist queries and their contact details will be available in the outpatient clinics. The link nurses will also be able to see the resources available in clinic areas which are available for patients and families.

## Resources

The network website also provides a huge amount of resources for the link nurses to direct patients and families to – please take a look at the patient and family section and the link nurse section: [www.swswchd.co.uk](http://www.swswchd.co.uk)

## Support and learning: Network-wide link nurse days



The Network's second link nurse day was held in Taunton on 6<sup>th</sup> January, with twelve paediatric/community nurses and six adult congenital link nurses attending. The meeting consisted of presentations on the CHD

network; red flags for community nurses; transition; complex case discussion; understanding the Bristol clinical nurse specialist service and working collaboratively. The day was evaluated very well and the plan is to hold these days every six months when this is possible.

**The next Network Link Nurse Day** is due to be held in July 2020 and may be held remotely if required. For Link Nurses interested in attending, please email [rachel.burrows2@uhbw.nhs.uk](mailto:rachel.burrows2@uhbw.nhs.uk)



## Interested in becoming a link nurse? Here is what to do...

Take a look at the link nurse/CHD nurse job description. This can be found on the network website:

<https://www.swswchd.co.uk/en/page/chd-achd-nurses-link-nurses>

For more information please contact Network Lead Nurse Sheena Vernon

[Sheena.Vernon@uhbw.nhs.uk](mailto:Sheena.Vernon@uhbw.nhs.uk)

## British Adult Congenital Cardiac Nurses Association (BACCNA)

In March 2020 a national meeting was held in Birmingham for the Adult Congenital Heart Disease Nurse Specialists. There were 25 delegates present from across the UK. The day was a highly valuable opportunity for learning and service development.

To find out more visit: <https://baccna.org.uk/>

# In memory of Wendy

## Adult Congenital Clinical Nurse Specialist from 2006-2019

Many of you will be aware that Wendy Visser, a long standing member of the Adult Congenital Heart Disease (ACHD) team, sadly died after a period of ill-health in September last year. Wendy's contribution to the team was acknowledged in the UH Bristol Recognising Success awards in November, and members of the team were proud to accept Wendy's award on her family's behalf.

Wendy was an integral part of the ACHD team at the Bristol Heart Institute (BHI). Having moved to the UK with her family from South Africa, Wendy joined UH Bristol in 2002 and worked with the ACHD team since 2006.

In 2008, Wendy joined Sheena Vernon as an ACHD clinical nurse specialist. The ACHD clinical nurse specialist team then expanded in 2012 with the arrival of Bethan Shiers, who is now working as an ACHD clinical nurse specialist in Cardiff. The role of the specialist ACHD nurse changed significantly during Wendy's career, and she helped to develop the service within her role, whilst always putting patient care at the heart of everything she did.

### Clinical interests

Wendy enjoyed all aspects of her role. She supported in-patients, out-patients and those calling the telephone advice line when support was needed on questions on cardiac surgery, cardiology procedures and cardiac obstetrics. Wendy had a passion for caring for patients with learning disabilities, and she worked hard to support patients and their families when the patient was attending an outpatient appointment, or as an in-patient. Wendy worked tirelessly to ensure their admission went as smoothly as possible. She was also interested in pulmonary hypertension as well as supporting young people as they transferred to the adult services.

### Educational interests

Wendy was always keen to learn, attending many courses and conferences to develop her knowledge. She also enjoyed teaching both students and qualified nurses locally and at the University of the West of England.

Wendy was popular with patients and staff alike. For many patients she played a significant part in supporting them through their cardiac journey. She was devoted to her family, particularly her two sons, her daughter-in-law and her baby grandson.

Wendy is greatly missed by the ACHD team, the wider teams in the Bristol Heart Institute and the patients she cared for.



Wendy Visser, specialist adult congenital heart disease nurse

HIGHLY COMMENDED



## Education and Training

The network has continued to work to implement the standard for education across the CHD Network which includes *ensuring the ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.*

Details of all training and education events can be found on the [network website](#). A number of specialist training days, including inherited cardiac conditions, fetal cardiology, national and international meetings, are also publicised there.

Future education opportunities will be considering the needs of **sonographers** who provide such an excellent echo service.

### What's coming up in 2020?

- CICU Education day, Bristol, 23 July
- CNS (level 1 and 2) Away Day, Cardiff, 28 July
- 12<sup>th</sup> Advanced Symposium on ACHD, London, 21-22 September
- ACHD study day, Bristol, 14 October
- BCCA Annual Meeting 2020, Birmingham, 11-12 November

## Lesion of the month

As part of the CHD network **education plan for 2020**, there is a bitesize education resource circulated called "*Lesion of the Month*". A lesion refers to each of the individual cardiac conditions. These include the common congenital heart defects:

- Atrial septal defect
- Patent foramen ovale
- Ventricular septal defect
- Pulmonary stenosis
- Aortic stenosis
- Coarctation of the aorta
- Tetralogy of fallot
- Transposition of the great arteries.



The resources are prepared by the adult congenital clinical nurse specialist team and circulated to nurses and clinical teams across the network. These are excellent resources for those who want to understand the lesion in more depth. If you would like to receive "lesion of the month" information please email [rachel.burrows2@uhbw.nhs.uk](mailto:rachel.burrows2@uhbw.nhs.uk)



## THE PREGNANCY PATHWAY

A new pregnancy pathway has been developed for patients with congenital heart disease who want to understand more about their ante-natal journey. This can be found on the network website under the [patient pathways adult section](#) of the website.

All women with congenital heart disease should be offered pre-pregnancy advice from their Adult Congenital Heart Disease (ACHD) Cardiologist. It is best if the pregnancy is planned.



### Did you know...?

The **dental pathways** for children and adults with congenital heart disease can be found [on the network website](#).

## Network Dates for your Diary!

### Key Network Meetings in 2020:

- 23 June:** Network Board meeting
- 15 September:** Network Board meeting
- 8 December:** Network Board meeting



# Welcome to the Network!

## Dr Shafi Mussa

The Network would like to introduce the consultant congenital cardiac surgeon who joined the Bristol team in December 2019



*"I was delighted to be appointed as the fourth congenital cardiac surgeon in the Bristol team, and I am really looking forward to making a contribution to the Network"*

**What are your interests?** I am interested in surgery for all aspects of congenital heart disease, but my particular interests are neonatal surgery and aortic surgery in adult congenital patients.

**Where did you train?** I trained in congenital heart surgery at Birmingham Children's Hospital, Great Ormond Street Hospital and the Evelina London Children's Hospital, and the Necker-Enfants Malades Hospital in Paris. I hope to bring some of that experience to Bristol.

I also have a passion for education and training, and I am looking forward to be heavily involved in teaching across the Network.

**What about life outside of work?** I am married with three boys, and my family and I are excited about seeing what Bristol and the South West have to offer!

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## Cardiac surgery - patient pathway film premiere

The Bristol Heart Institute have created a series of short films to help patients know what to expect pre-surgery, on the day of surgery, immediately after surgery, and once they are discharged. These can be found on their website:

<http://www.uhbristol.nhs.uk/cardiacsurgeryjourney>

Video 1: Pre-operation



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

Welcome to Rachel Burrows, as the network support manager for the South Wales and the South West. Rachel will be a great support in helping the network to deliver its ambitious work programme. To find out more, check out Rachel's profile on our website ([www.swswhcd.co.uk](http://www.swswhcd.co.uk))

Congratulations to Dr Patricia Caldas, consultant paediatric cardiologist and lead fetal cardiologist, who has taken on the role of clinical lead for paediatric cardiology at the Bristol Royal Hospital for Children.

Welcome to Beth Brock and Sophie Morland, new paediatric clinical nurse specialists at the Bristol Royal Hospital for Children, and also to Hannah Williams and Lisa Winfield, new ACHD clinical nurse specialists at the Bristol Heart Institute.

Welcome also to Melissa Winn, service manager for cardiology and CFS at the Royal Cornwall Hospital, and to Sophie Nicholls, general manager at the Bristol Heart Institute.

We are sad to say goodbye to Rob Tulloh, consultant cardiologist, who has retired from the Bristol Royal Hospital for Children. We wish Rob a happy and healthy retirement!

## Network team on tour!

One of the key aims of the South Wales and South West Congenital Heart Disease (SWSW CHD) network is to support its hospitals to deliver the standards set for Congenital Heart Disease (CHD) care.

The CHD standards, set by clinicians and published in 2016 by NHS England, describe the way in which CHD services are to be organised and run. They help to ensure that all patients have access to high quality care and minimise differences between different hospitals. They cover a wider range of subjects from staffing to dental care. Find out more by [visiting the NHS England website](#).

Over the past few months, the CHD network team has been visiting CHD teams across the South Wales and the South West to understand how teams and services are currently doing, how they are delivering the standards and what support or help they might need with the standards they are not yet able to meet.



Following the visit, each team will receive a report which details any areas of best practice and recommendations/are next steps. When all the visits are completed, a network wide report will be drafted that celebrates these areas of best practice, to share learning across the network, and also to highlight the key challenges that CHD services are facing and any help support they may need to address these.

The network team would like to warmly thank all those centres who have been so welcoming during these visits and they look forward to meeting more teams in the near future.

### Key headlines to date

- 9 centres visited and 7 to go – these visits are currently on-hold due to the Covid-19 pandemic.
- So far, good progress has been made in the majority of centres with gaps in standards being addressed where possible.
- Ongoing challenges for services include local ACHD service provision, participation in Multi-Disciplinary Team meetings, image sharing and establishment of the link nurse role
- New ways of working with benefits for patients, staff and services have been highlighted. These include cardiac physiologist led clinics and virtual clinics.



### It's a national affair...

#### Did you know that the South Wales and South West CHD network is part of a bigger national network?

Whilst the South Wales and South West CHD network was one of the first CHD networks to be set up in 2016, there are now around 11 other CHD networks across the country.

Every six months there is a national CHD network event for these teams to come together, share learning and best practice, and to highlight any challenges and/or issues that may need to be addressed nationally.

At the last meeting, held in December, Michael Wilson, national programme director for Congenital Heart Disease, reported the key findings from the national peer view. Watch this space for more details on this!

In response to the COVID-19 pandemic the national networks have been having weekly conference calls to support CHD services during this challenging time. Following this there is a fortnightly South Wales and South West CHD network conference call.

If there are any particular issues or topics you would like raised at these forums then please contact Cat McElvaney, South Wales and South West CHD Network Manager via email

[Cat.McElvaney@uhbw.nhs.uk](mailto:Cat.McElvaney@uhbw.nhs.uk)



# Cardiac imaging in CHD

By Dr Nathan Manghat, consultant cardiovascular and interventional vascular radiologist, and Dr Dina Mitrousi, cardiac MRI fellow – Bristol

Cardiac imaging plays a vital role in the diagnosis and surveillance of patients with congenital heart disease. Cardiac Magnetic Resonance Imaging (MRI) scanners use a strong magnetic field and radiofrequency waves in order to generate moving images of the heart and connecting structures. MRI does NOT use radiation. The imaging provides detailed anatomical, functional, flow and perfusion information. These scans may take up to 1.5 hours to acquire.

Cardiac Computed Tomography (CT) scanners use an X-ray tube and detectors that rotate around the patient's body to create detailed images of the heart that allow complex reconstructions, 3-dimensional images and even facilitate 3-d printing of complex anatomical models that can assist surgeons. These scans can be acquired in only a few seconds. The latest scanner technologies that we use allow us to hugely minimise radiation doses compared to 10 to 15 years ago.

There is a very small but existing risk of allergic reaction to the different contrast agents ('dyes') used for both techniques.

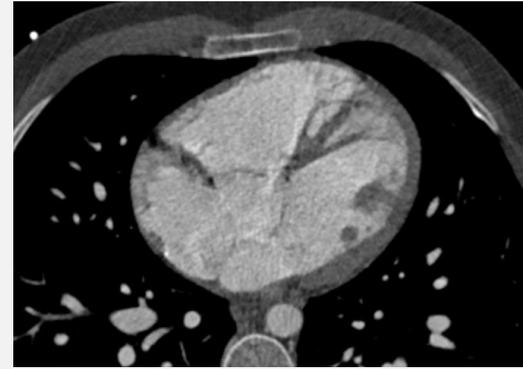
These modes of taking images are complimentary to one another. Along with echocardiography (cardiac ultrasound); they contribute to minimising overall morbidity and mortality, and provide important information to allow best estimation of the timing of further surgery, such as a valve replacement or closure of abnormal cardiac connections.

Even after childhood operations, it is desirable to have lifelong follow-up as there is always a risk of potential post-operative complications. The absence of symptoms does not mean that a disease is not progressing and that the scan is not important.

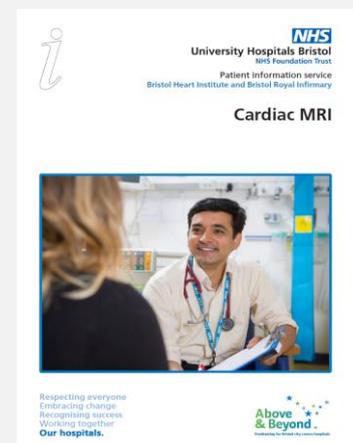
Congenital scans are considered to be some of the most complicated and time consuming studies both for image acquisition (performed by a specialist radiographer) and the detailed analysis (performed by doctors who are either cardiac radiologists or cardiologists with an interest in imaging).

The initial congenital scans may take 60 to 90 minutes, which requires patients to stay as still as possible whilst performing multiple relatively short breath-holds. Follow-up scans may be shorter and more focused to answer specific clinical questions, and these studies may last 30 to 40 minutes.

It is important that patients understand what to expect from each scan as the rates of patient non-attendance can be high, especially among younger patients who might otherwise feel fine and that their scan is not necessary. This causes wasted NHS resources in a precious and limited service at considerable expense, which might also prevent another patient having the opportunity of a scan. The scans are discussed in multidisciplinary team meetings which include cardiologists, cardiac surgeons, cardiac radiologists, cardiac anaesthetists and specialist nurses.



**Patient information leaflets** are available on the [Bristol Heart Institute pages](#) of the UHBW website.



# Our first network specialist psychology day

By **Dr Vanessa Garratt, clinical psychologist, and Ryan Kay, psychology assistant**

To support the growing number of psychologists in the network, we held our first specialist psychology network day in February 2020. The aim was to bring together psychologists, therapists and support practitioners, who may work with cardiac families, to raise awareness of the network, share knowledge and practices relating to congenital heart disease, and to develop links between psychologists working at various centres across the South Wales and South West region.

## Presentation topics included:

- An overview of the CHD network as well as the paediatric and adult psychology services
- Information regarding smooth transition of care from specialist centres to local hospitals
- Guidance for supporting CHD patients and their families



## Delegate feedback:

The overall feedback from the 20 delegates that attended the event was positive. Many of the attendees reported that the talks were of a high quality and were useful in developing their skills, as well as learning more about psychology in the setting of congenital heart disease.

It was also a fantastic opportunity for cross-networking and peer support. One delegate commented: "It has been great to meet colleagues, share service development ideas, learning, and resources. It has made me think more about a lifespan approach to long term conditions."

## What's next?

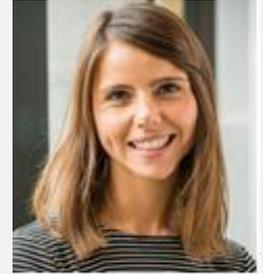
Ideas generated from group discussions at the network psychology day have been fed back to the psychology network to think about ways to work more closely together in the future, this may include an annual psychology training day, establishing a psychologist bulletin, or representing the range of services within the psychology network at future network meetings.



## Our psychology services

Our specialist psychology services across the network are growing and changing.

We are delighted to welcome **Sam Lloyd, psychologist in paediatric cardiology, at Bristol Royal Hospital for Children.**



In **Cardiff** we are saying a warm welcome to **Llinos Griffiths**, new psychologist who joined the paediatric service in March.

In **Taunton**, we are saying a sad goodbye to **Kat Peckitt**, clinical psychologist, who left in February. We are grateful to Kat for her support to the network and wish her all the best.

## Update on social media campaign: #myquestion

A #myquestion campaign has been conducted to respond to common questions or concerns from CHD families, offering support and signposting to a number of helpful online resources. The campaign has been run on the Bristol Royal Hospital for Children and local support group Facebook pages. It has also been shared on the network twitter: 

[@chdnetworksws](https://twitter.com/chdnetworksws)

Evaluation of the campaign is underway with a plan to conduct future campaigns if helpful.





# Transition & Young People



Paediatric transition clinics have been underway in the Bristol Royal Hospital for Children for three years. Consultant clinics are booked with young people aged 12 to 16 years on a regular basis and the clinical nurse specialists are available to support the clinics. These clinics are used to help prepare paediatric patients as part of their transition to adult services.

## Young people clinics

For patients between the ages of 16 and 24 years, young people clinics are held regularly in the Bristol Heart Institute. These clinics see young people on their first appointment in the adult services. They are an opportunity to strengthen patient education about their cardiac condition, their medication, lifestyle issues, recognising the symptoms of endocarditis and understanding the risk. The clinics also cover discussing appropriate contraception, any risk during pregnancy and the possibility of the inheritance of congenital heart disease. These clinics are also supported by Xander Cook, youth worker at the Bristol Heart Institute.

South Wales also has a fantastic transition service which has been in place for some time and young people's clinics are in development by the adult services.

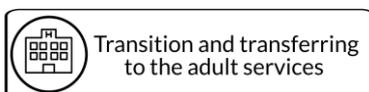
## Setting up transition clinics across the region

Work is now underway to look at progressing this in our Level 3 clinics. The aim would be to support two transition clinics a year, for patients aged 12 to 16 years in all the level 3 clinics.

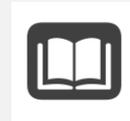
Paediatric clinical nurse specialists from Bristol will attend the appointments. They will support the paediatrician with expertise in cardiology, and the visiting consultant cardiologists as they see patients and begin to discuss the transfer to adult services and start discussing the issues outlined earlier in this article. An additional room will be required for the clinical nurse specialist, so they have time with the patient and family to answer questions and provide support.

## Resources

There are a number of excellent resources for transition that can be accessed on the [CHD Network website](#) and on the [British Heart Foundation website](#).



## Academic Journal Review



By Professor Graham Stuart

The *Journal of Congenital Cardiology* is a new online journal publishing in all areas of congenital cardiology. It is published by BiomedCentral from the prestigious Springer Nature group of journals.

Submissions are welcomed on all subspecialties, including (but not limited to) genetics, epidemiology, electrophysiology and interventions. The Editor in Chief (Prof Graham Stuart) and several clinicians in the South Wales and South West Congenital Heart Network are members of the editorial team.

The journal publishes expert reviews, research articles, short series and case reports and is "open access", which means that the articles are free to download by clinicians and patients alike.

By bringing together open-access research and knowledge published in these areas, *Journal of Congenital Cardiology* aims to provide an essential resource for cardiologists, surgeons, general practitioners, researchers and healthcare professionals interested in congenital heart disease.

To date there have been over 24,000 articles downloaded. The Editorial Board welcome article submissions and suggestions for scientific reviews, and would be delighted for articles to be downloaded by network members. Links to Professor Stuart's introductory editorial and the journal website are below.

[Website](#)

[Introductory editorial](#)

# Music to my ears and mind

## From brass band to surgery: a young cardiac patient's musical journey of anxiety reduction

By Claire Fraser-Tytler, senior music therapist

Louis is a sixteen year old who was born with congenital heart disease. He was referred for procedural support and music therapy at Bristol Royal Hospital for Children to help prepare him for open heart surgery, having had numerous previous surgeries. This surgery had already been cancelled twice due to his high anxiety.



Music therapy is an effective way of processing difficult emotions surrounding diagnosis and treatment pathways without having to use words, which can sometimes be challenging.

At the children's hospital we work with a wide range of patients. We

use percussion, drums, ukuleles and other musical instruments that we either take to the patient's bedside or to the play rooms for group sessions.

Louis began playing music at the age of two when his brass band playing parents bought him a trumpet. Since then he has moved onto the euphonium, and playing in brass bands has been an important part of his life. His heart condition meant that he was unable to play the euphonium to his full potential as his breathing capacity was compromised.

Before becoming a music therapist, I was a professional French horn player and use my red plastic trumpet on the wards throughout the hospital. I was able to use my brass playing skills to help calm Louis enough to come to the hospital. For a year prior to the operation Louis and his mum came each month to a joint music therapy and psychology session. These joint sessions allowed the psychologist to support mum with strategies to help Louis at home whilst I played duets and talked to him about how music might help his anxiety.

On the day of his operation, Louis and I played pre and post his preoperative medication and used Spotify to play some music to calm him.

This photo is from when Louis came back to the hospital to play some duets and have a final session with me, eight months after successfully undergoing his operation. He brought with him his new euphonium, purchased with the bursary he was granted for being an outstanding musician.



Thanks to the combined efforts of the wonderful medical team, the psychologist and music therapy, Louis now has a bright future ahead of him and has recently started a barbering course.

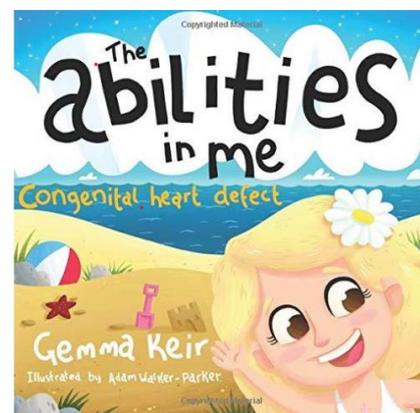


Music Therapy at the Bristol Royal Hospital for Children is funded by **The Grand Appeal Charity** and provided by **MusicSpace**, a charity which provides music therapy across the south west for people with a wide range of conditions.

To find out about The Grand Appeal please visit [www.grandappeal.org.uk](http://www.grandappeal.org.uk)

To find out more about music therapy and finding a music therapist please visit [www.musicSPACE.org](http://www.musicSPACE.org)

## Network Book Club!



This bright, colourful and fun picture book is dedicated to children with CHD. For children, parents and teachers, it helps bring awareness of the condition and teach children how to be supportive and kind. Authored by Gemma Keir as part of her "The Abilities in me" range, this book is aimed for children between the ages of 3-8 years. Enjoy!



## 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 ([www.swschd.nhs.uk](http://www.swschd.nhs.uk))

### Flashback to the Childrens Cardiac Christmas Party!

Last year, the Bristol Royal Hospital for Children's charity, The Grand Appeal, working in partnership with the outstanding nursing team from Dolphin Ward, brought together incredibly courageous children who underwent heart surgery throughout 2019 for some festive fun at their annual cardiac children's party. Hosted at the Bristol Marriott Royal Hotel, the party was a great opportunity for patients, parents, and staff to celebrate the inspirational journeys of these remarkable young people.



*"This event is always so popular, with over 300 people coming along. It is a fantastic afternoon for families to catch up with the nurses, surgeons and doctors who looked after them along with other families they may have met during their stay. It was lovely to see so many people and hear so much laughter after what has been a tough year for some of our patients."*

*Zoe Trotman, sister on Dolphin Ward*

## Youth @ Heart: The Rescue Rucksack

By Xander Cook, ACHD Youth Worker



The Rescue Rucksack is my inpatient support tool kit. It started life as a grey branded (Youth@Heart) bag. I then filled it with some games, it currently has Uno, Exploding Kittens, a deck of cards, Dobble, a Top Trumps game, a Drag Queen Top Trumps game, a book on Queer icons and a couple of colouring books that are aimed at adults.

To make it more fun I ordered a pack of 50 sew on patches and the young people I support get to pick a patch and where they would like it placed. I then take the badge home to my fiancée who kindly sews it on for us. Here is some of the feedback Xander has received:

*"We mainly played card games which I really enjoyed and took my mind off why I was in hospital and cheered me up for the time that he was there"* Male 22 years

## 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.



## Thank you for reading!

If you have any stories or ideas you would like to share for the next edition in **Autumn 2020**, please contact [Rachel.Burrows@uhbw.nhs.uk](mailto:Rachel.Burrows@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.swschd.co.uk](http://www.swschd.co.uk)