South Wales and South West
Congenital Heart
Disease Network

October 2017
Issue 3

Newsletter

Network Team Update

The team has now been fully established for 12 months and is into its second year of an ambitious programme of work. At the end of August we bid farewell to James Dunn, who was in post as Network Manager covering Caitlin Moss (nee Marnell's) maternity leave. We want to thank James for all of his hard work during this time, and wish him well in his future endeavours.

Since the last newsletter was published, the first annual report on the Network's activity has been written. (It is available here: https://tinyurl.com/yb4jv6zm, for those who may not yet have seen it.) The report highlights the Network's achievements in its first year of operation, its ongoing challenges and future plans.

We are now working on our Year 2 priorities, which include:

- Launching our new **website**, which will be a useful resource for both patients/families and clinical colleagues
- Continuing to support our centres to meet remaining **gaps** in their services, as required by NHS England's challenging **service standards**
- Developing and sharing more **clinical best practice and guidelines**
- Developing our **research, audit and governance** programmes
- Making best use of **technology** in order to improve communications between centres and with patients
- Strengthening our partnerships with relevant **charity and support groups**
- Continuing to roll-out **training and education** opportunities for the Network
- Continuing to listen to our **patients and carers** to make sure we are focusing our efforts in the areas that matter to them

If you want to find out more or get involved in any of our areas of work, please get in touch directly with the team. (Our contact details are listed in the right hand column.)

Website Development: Get involved!

After a formal procurement process, we are delighted to have now appointed a website design company called ***WebBox*** to undertake the technical design of our new website. However, the content is all down to us, and you!

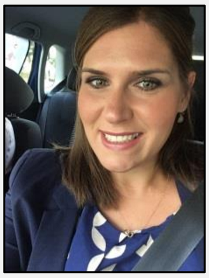
If you would like to be involved in one of our focus groups to help design and test the website before it goes live, please email Caitlin.Moss@uhbristol.nhs.uk as soon as possible. We are looking for health professionals, patients and family members/carers to take part in these groups in early November.

Key contacts

Clinical Director: Dr Andrew Tometzki
Andrew.Tometzki@uhbristol.nhs.uk

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

Network Manager: Caitlin Moss
Caitlin.Moss@uhbristol.nhs.uk



Network Administrator: Rachel Benefield
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Charity Focus

Nine years ago, a 16-year-old girl (Alice), who had been born with complex Congenital Heart Disease, wrote a speech in which she outlined the daily challenges she faced. She wrote of the isolation and frustration that living with CHD led her to experience, and explained that she was inspired to create a charity for other young CHD sufferers, offering the support that she felt had not been available to her. Although there was awareness of disability, she found there was no real understanding of the impact of the condition, not just on the patient, but also on their families, friends and carers.

Alice thought about an appropriate name for her charity, designed a logo and began to map out her vision. The principle of Youth@Heart had been born! Everyday life became increasingly challenging for Alice, and although the idea for her charity was superb, it was never going to be easy for her to realise it. Sadly, Alice lost her battle and died in 2013, aged just 22.

Following Alice's death and after conversations with the Bristol Heart Institute, her family decided they would realise her vision and with the help of friends, formally initiated the charity. Youth@Heart became a registered charity in August 2014 and now, three years on, is well over half way towards raising the target figure of £100,000 from a variety of events and activities.

The aims of the charity remain as Alice mapped out nine years ago. They are to:

- Support young people aged 16-24, and their families, living with Congenital Heart Disease across the South West
- Increase awareness and understanding of the challenges that living with CHD imposes on young people and their families. (This includes improved training opportunities about CHD for non-medical professionals encountering congenital heart disease patients)
- Employ a Cardiac Youth Worker to facilitate opportunities for CHD patients to maximise their potential

Further information is available on the charity's website: www.youthatheart.co.uk and social media pages, or you can contact them directly by email: contactus@youthatheart.co.uk.

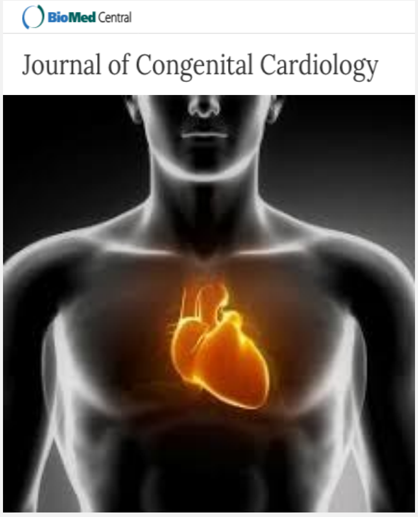
New Journal Alert

The Journal of Congenital Cardiology is a new online journal publishing in all areas of congenital cardiology. It is being published by Biomed Central – a member of the highly prestigious Springer Nature publishing group. The journal follows the open access model of publishing which means that the articles are freely available to all researchers, patients and clinicians.

The Editor in Chief is Dr Graham Stuart, Consultant Cardiologist in the Bristol Congenital Heart Unit. In addition, Bristol has several representatives on the International Editorial Board including Professor Massimo Caputo, Professor Rob Tulloh, Dr Mark Turner and Dr Guido Pieles. Submissions are welcomed on all subspecialties including (but not limited to) genetics, epidemiology, electrophysiology and interventions.

The journal will publish expert reviews and latest research articles. Short series and case reports may be also considered if they provide a unique or notable insight into the aetiology, diagnosis or management of a congenital heart condition.

https://jcongenitalcardiology.biomedcentral.com/.



Cardiac Nurse Specialist in Fetal

Since last year, the Fetal Cardiology Service at University Hospital of Wales, has received new funding from the Welsh Health Specialised Services Committee (WHSSC) to help provide a comprehensive service for South Wales, based in Cardiff.

The aim was to increase the number of fetal cardiology clinics per week, by funding additional consultant sessions, as well as a part-time Cardiac Nurse Specialist (CNS). This has had a huge impact on waiting times for pregnant women. There was also provision for a sonographer and a health care support worker to support the new clinics. The team work closely with the Fetal Medicine Department.

During the clinic, the role of the CNS is paramount in supporting women and their families through all stages of their journey. The CNS is the first person they come in contact with during clinic before the fetal heart scan is performed and usually the last point of contact before leaving the clinic.

Children's Heart Unit for Wales
Uned Calon Plant I Gymru

When a person has been given bad news from a medical professional, evidence tells us that only a small amount of information is taken in. People can be stunned by the news they hear and may not fully remember what they are told. Some parents-to-be who have been in that position, have said they would have liked more information to take away with them. Therefore, one of the main roles of the CNS is to provide comprehensive written information for families.

The CNS continues to offer support to meet the individual needs of pregnant women and their families, by giving advice and education about the diagnosis and treatment throughout pregnancy. The social and emotional needs of the individual women are taken into account.

Another important aspect of the role is to liaise with the fetal medicine units in Cardiff and Bristol (when necessary) and women's local antenatal units to ensure everyone has up-to-date information.

When serious heart defects are detected, a team of experts is in the best position to provide detailed information, discuss options, make plans for the rest of the pregnancy, plan for a safe delivery and provide much needed support for the family. The CNS is a key member of this team.

Useful websites for families

Bristol Royal Hospital for Children

http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/

Antenatal Results and Choices

http://www.arc-uk.org/

British Heart Foundation

http://bhf.org.uk/

Children's Heart Federation

http://www.chfed.org.uk/

Heartline

http://www.heartline.org.uk/

Down's Syndrome Association

http://www.downs-syndrome.org.uk.uk/

Max Appeal-22q del11

http://www.maxappeal.org.uk/knowledge/22q11.2-duplications

South West Children's Heart Circle

http://www.heartcircle.org/

Amelia Matters

www.amelia-matters.org.uk

Contact a Family

http://www.cafamily.org.uk/

Meet one of our adult patient representatives

My name's Becky Nash. I'm a CHD patient in Bristol, but originally from Cornwall. More importantly, I'm a 31-year-old wife, mum to my young son, and a nurse. Here's my story…

I have had two open heart surgeries, firstly in 1996 aged 10 and, more recently, in March 2016. It's amazing how the innocence of childhood comes into play, as I do not recall much of my earlier operation. What a different story this time!

There is no doubt that last March/April was the hardest time my family or I have ever experienced. Nothing could have prepared me for saying goodbye to my husband and son before the operation (my son was only three at the time). However, I was confident I couldn't be in better hands.

In the aftermath of the surgery, what hit me the most was how overwhelmingly weak I felt. I was scared, I was in pain, I felt sick and had absolutely no energy, but the CICU team at the BHI were amazing.

"I cannot thank the teams at the BHI and Treliske enough, I literally owe them my life. A special thanks to Mr Parry and Mr Stoica, who carried out my operation. Together you all made an awful time that little bit better for my family and I."

I was so relieved 10 days later to return home to Cornwall, where I then lived. I was desperate to see my little boy, who had been staying with my in-laws.

Unfortunately my recovery was delayed by continued rhythm issues within the heart, a complication of the complex surgery. This resulted in an emergency admission to Treliske hospital in Cornwall, to have a permanent pacemaker fitted in the early hours of the morning four weeks post-operatively. This was terrifying.

I'm pleased to say that my recovery went from strength to strength after the pacemaker insertion. I felt better almost immediately and was home later that same day!

Onwards and upwards: I'm looking forward to a happy and healthy future being the best mum, wife and nurse I can be. I am delighted to now be part of the CHD network as a patient representative. I am really enthusiastic to help in whatever way I can, as facing heart surgery, or indeed living with a lifelong condition, is such a difficult thing for patients and their families. My role includes offering opinions or viewpoints during board meetings from a patient's perspective. I am really hoping that my career in nursing also helps me offer helpful opinions from a clinical perspective. Either way I am thrilled to be even a small part of the network and the hard work they are doing.

Fantastic Pharmacy

***Insights from Susie Gage, the Paediatric Pharmacist at the Bristol Royal Hospital for Children*.**

As part of the multidisciplinary team, it is a pharmacist's job to consider the safe and effective use of medication. In paediatric care, we often hear the phrase; 'children are not mini adults'. So what are the challenges in paediatric care?

Patient weight ranges from a baby to adolescents (<2kg to >100kg). Dosing calculations can be carried out by various methods; by weight, surface area or age. As a child grows what the body does to a drug changes (pharmacokinetic changes). This means thinking about kidney and liver function and where the drug is excreted. There are also changes to what the drug does to the body (pharmacodynamics changes). This can also involve undertaking drug levels for a particular medication to check for toxicity and optimum therapeutic response.

Many formulations used in paediatrics (liquids, suspensions, tablets, capsules etc.) are licensed for adult use. The problem comes in what else is incorporated into those mixtures, what we call excipients. An example is the alcohol content, which we try and keep to a minimum for paediatric patients. At times there are no liquid formulations available so you may need to crush a tablet. We then need to consider the impact of this regarding absorption and effectiveness of the medication.

There are also a number of different strengths of liquids, which can cause huge confusion when a child is discharged from hospital and the GP continues the repeat prescription, but at a different strength. Furosemide and spironolactone are classic examples where multiple strengths are available.

There have been advances nationally to deal with some of these challenges; such as children's drug formulary (BNF-C), children's research network and sharing of good practice and innovation via Neonatal and Paediatric Pharmacists Group (NPPG). One such idea was the medicines for children leaflets that parents/carers can access (http://www.medicinesforchildren.org.uk/).

What other areas do we get involved in?

A large part of a pharmacist's day involves giving medicines information to clinical staff and families.

Many GPs do not prescribe the specialist medication needed for our patients so we try to have a seamless approach across the Network, to make life easier for parents/carers to organise a supply of these medications from their local hospitals.

We get involved in cost effectiveness and funding approval requests for new drugs or treatments in line with Department of Health funding streams.

We deal with issues around the supply of drugs and sourcing alternatives from specials manufacturers.

We get involved in research with clinical trials and audit work.

We support risk reduction, and governance around the medication we use.

So, with all of this this in mind, don't be afraid to ask to speak to your pharmacist, if you have any questions about your/your child's medication.

Waiting times for patients

The NHS Constitution for England outlines the principles and values of the services it offers to patients. It highlights that patients have the right 'to access certain services commissioned by NHS bodies within maximum waiting times, or for the NHS to take all reasonable steps to offer you a range of suitable alternative providers if this is not possible.'[1]

All patients in England can expect to be treated at the right time and according to their clinical priority. They should be able to start consultant-led treatment within 18 weeks from referral for non-urgent conditions; and those with urgent conditions should receive treatment more quickly. The NHS in Wales is slightly different and the target for non-urgent patients to receive care is within 26 weeks. This presents a challenge for us as a Network covering areas in both England and Wales, as inequity exists.

The performance of all NHS organisations is monitored against waiting time standards. As a Network team, we also monitor waiting times for patients across all of our Centres, be they Level 1 (Specialist Surgical Centres – University Hospitals Bristol), Level 2 (Specialist Centres – University Hospital of Wales) or Level 3 (Local Centres). We review the data every three months at our Network Board meetings, the membership of which includes many clinicians and several patient representatives. This is part of our remit, as outlined in the new CHD standards, (detailed in the right hand column).

Data is given to us on a voluntary basis and in September 19 centres responded to our request. (This is from a total of 36 centres - a 53% return rate). Of the responses received, 13 of 19 centres were meeting their required waiting times for new outpatients; and nine of 19 for follow-up outpatients.

We want to work with our centres to ensure they have adequate capacity to provide patients with the right care, at the right time. If you are a clinician or manager within the Network, please help us by providing data in a timely manner, and please get in touch if we can offer you any support in this area. We can help with demand and capacity modelling tools, business case development and are happy to come to your hospital for face-to-face support.

The standards state that:

Each Congenital Heart Network will hold regular meetings of the wider clinical team for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months.

Network patient representatives will be invited to participate in these meetings.[1]

Spotlight on Audit!

The Network wants to pull together an audit programme over the coming year and beyond, in order to share learning across the region. **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 Sheena.Vernon@uhbristol.nhs.uk or Andrew.Tometzki@uhbristol.nhs.uk

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[1] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/480482/NHS_Constitution_WEB.pdf

Outpatient Improvements in the Bristol Royal Hospital for Children (BRHC)

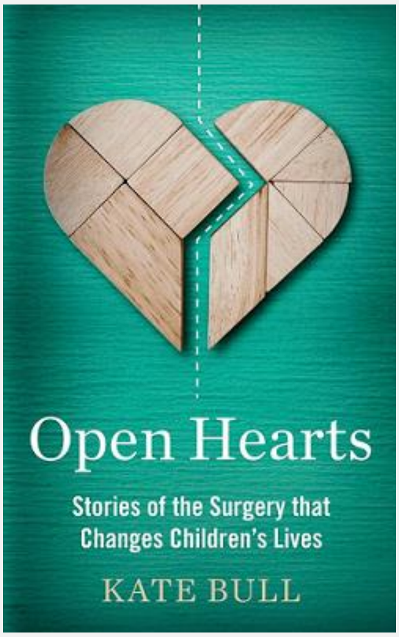
The BRHC has been preparing for the change in patient appointment booking systems towards ‘partial booking’. This means that rather than being sent a fixed appointment, patients will be sent a letter asking to call in and arrange an appointment time that works for them. The aim of this is to improve patient experience and reduce the number of patients who do not attend, and thus make the best use of the capacity available. Members of staff are currently undergoing training ready for the switch.

A plan for the transition of appointment booking services to the hospital’s central Outpatient Appointment Centre has been put together. This should make it easier for patients to get in touch with the hospital.

Work with clinical, nursing and management teams has been ongoing to plan the clinic space needed in outpatients to deliver the right number of Cardiology clinics to meet the needs of patients. With the arrival of Dr Catherine Armstrong to the Paediatric Cardiology Consultant team the number of clinics provided by the service will be increasing over the coming months.

The BRHC has been exploring ways of expanding outpatient services with a recent patient survey asking for feedback on the idea of earlier and later weekday appointments and opening of the department on weekends. They were delighted with the number of responses, which showed that weekday evening and weekend day time appointments would be very popular with the many families. A piece of work will be under way shortly to understand the feasibility of expanding the opening hours of the outpatient department and impact on clinical teams.

Book Club Suggestion



Kate Bull qualified in medicine from Cambridge University and has specialised in the treatment of congenital heart disease at Great Ormond Street Hospital since 1979. Both highly regarded practitioner and academic expert in her field, she also has a particular respect for the experiences of patients and parents. She has interviewed many patients and their families and heard their stories.

The Independent review:

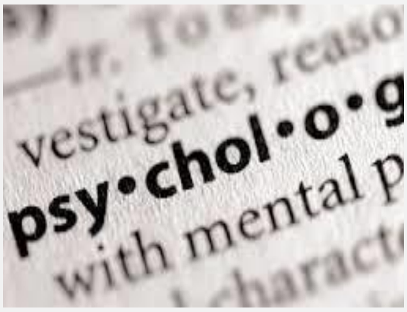
‘Full of the wry humour of medicine… Bright, lively and always alert to the patient’s perspective.’

Psychology Support for Adults with CHD

Significant advancements in diagnosis, investigations, medical treatment and cardiac surgery over the past century have meant that many patients with Congenital Heart Disease (CHD) are living longer and healthier lives. Positively, a condition that used to be life-limiting for the majority of people has now become a more manageable long-term condition. As with other long-term health conditions, there are unique challenges that congenital patients encounter such as: frequent medical tests and repeated surgical procedures; uncertainty about the course of their condition and how it will impact on their lives; missed school or work for medical reasons; and struggles with family planning. This can lead people to experience a range of emotions including worry, anxiety, sadness, fear and anger. All of these emotions (and many more) are very normal and completely understandable.

The majority of people will be able to adapt to life with CHD but a number of people may really struggle. Their emotions may be difficult to manage and they may find that this has an impact on things that are important to them. Some patients may find it more challenging to cope in certain situations than others, for example around times when they require surgery. Research has shown that approximately a third of people with CHD will experience significant anxiety and depression. When people feel very anxious or depressed it can be especially hard to manage their condition, attend appointments, take medications or prepare for medical procedures.

The NHS England, Congenital Heart Disease Standards & Specifications, which were published in 2016, recognised the need for psychological support for patients with CHD. The South Wales and South West Congenital Heart Disease Network is mindful that we need to take both the physical and psychological components of a patient's wellbeing into consideration. As such, we are happy to announce that a psychology service for adults with CHD has been developed. A pilot programme is running until December 2017, in which patients under the care of the Bristol Heart Institute in Bristol can be referred by their Cardiologist or one of the Clinical Nurse Specialists for psychological input.



As part of the Congenital Heart Disease Lifespan Psychology Service, from January 2018 patients from across the Network can be referred by their local cardiologist. Patients can be referred if they are experiencing mental health difficulties as a result of their CHD or if their mental health difficulties are making it difficult to manage their condition. The network Clinical Psychologist, Dr Michelle O'Keeffe (pictured left), can offer patients up to six therapy sessions. The aim of treatment will be to work on treatment goals that are important to patients so they can experience an improved quality of life whilst living with their condition.

Thank you…

… for taking the time to read our newsletter. If you have any feedback on it, or ideas that you think would make a good addition to the next edition, please contact: Caitlin.Moss@uhbristol.nhs.uk