South Wales and South West
Congenital Heart
Disease Network

July 2018
Issue 4

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Newsletter

News from the Network Team

As the network completed its second year of operation in March 2018, we have been reflecting on progress made and the remaining challenges faced. Our latest annual report is now available on our website and we welcome any feedback you might have on this.

In March, we were delighted to launch the network website: www.swswchd.co.uk. The website has a section for patients and families with lots of information including online leaflets and a range of brand new 'digibooks'. Digibooks are documents containing resources for patients of all ages and their families to help them get support with some areas of their lives that are affected by having a congenital condition. (These can be found in the Getting Support section.)

The website also has a section for Professionals, with a broad range of clinical information (useful documents, guidance and protocols) across the lifespan services the network covers: fetal, children's, transition, adults, learning difficulties, palliative care and pregnancy. It details how to get specialist emotional support for patients through our newly launched regional psychology service, and contains information about training and education events.

On the site you will find lots more including information on the network, our governance and all of the hospitals in our network (like practical information like how to get there and who's who in each team). It outlines ways to get involved and how to get in touch. We welcome your ideas and feedback on the website to make it even better.

In July, we say goodbye to our Network Administrator, Rachel Benefield. Rachel has been with the network since 2016 and will be sorely missed. Thank you to Rachel for all of her support and hard work. We wish her well in the future.

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

We proudly support over 6,500 children and 8,000 adults with a congenital heart condition.

Babies and Children

When your baby or child is diagnosed with a

Teenagers/Young People

Adults

When you are diagnosed with a cardiac

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Key contacts

Clinical Director: Dr Andrew Tometzki
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Lead Psychologist: Ness Garratt

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Network Priorities Year 3

As we move into our third year of operation in 2018/19, some of our priorities include:

Paediatric guidelines

Developing the network's approach to dental care

Improving discharge communications from the Level 1 centre

Evaluating our new regional psychology service

Developing a network transfer and repatriation policy

Working more closely with our charity partners

Developing the role of our patient representatives

Continuing to deliver a strong training and education programme

Ensuring Level 3 centres are accessing appropriate income for their services in in England

Charity Focus

The British Heart Foundation (BHF) is one of the UK's best known heart charities and the research it has funded has contributed a huge amount to progress in the care of patients with congenital heart disease. Professor Massimo Caputo, a BHF top Professor at the University of Bristol and based in the network's Level 1 centre, is leading exciting research in the field. You can find out more his and his team's work on the BHF website.

Did you know? Through membership of the BHF Alliance, professionals may be able to access funding for learning and development.

The Alliance Scheme offers healthcare professionals (excluding doctors) access to learning grants, workshops, resources and events to support their professional development.

As well as funding research and development, the BHF has local teams that support local priorities. Their South West Health Service Engagement Team kindly funded an event set up by the South Wales and South West CHD network to bring together CHD networks from across the UK in May. The event was a great opportunity for networks to get together and share best practice as well as discuss opportunities to tackle shared challenges. Networks from across England, Ireland, Scotland and Wales have committed to working together in the future to improve care for patients with CHD and the next meeting is scheduled for October in Leeds.

The BHF also has some very high profile ambassadors. Ulrika Jonsson and Pippa Middleton took the time to visit wards in the Bristol Heart Institute and Bristol Royal Hospital for Children in December. Patients, families and staff enjoyed meeting them both and Pippa said "*It was a huge honour to spend time with such brave children and their peers to hear about their challenging journeys. I was hugely impressed by the extraordinary work being done by the medical team.*"

You can visit the BHF website for more information on: www.BHF.org.uk

What is WHSSC?

Welsh Health Specialised Services Committee (WHSSC) is a joint committee of the seven Local Health Boards (LHBs) in Wales. LHBs are responsible for meeting the health needs of their resident population but delegate the responsibility for commissioning a range of specialised services to WHSSC.

WHSSC's role is to plan, procure and monitor the performance of specialised services; to ensure that patients are central to commissioned services and that their experience of specialised services is of a high standard; to co-ordinate a common approach to the commissioning of specialised services outside Wales; and to manage the pooled budget for specialised services. All of this work is undertaken with ongoing engagement with patients, service users and professionals.

The Cardiac Commissioning Team at WHSSC is made up of: Andrea Richards, Specialised Services Planning Manager; Susan Kedward, Specialised Services Assistant Planning Manager and Dr Paul Flynn, Associate Medical Director for Cardiac Services, with support from IT and Finance colleagues.

The team are currently working with colleagues at the University Hospital of Wales in Cardiff and the South Wales and South West CHD network, to ensure that there is equitable access to safe, effective and sustainable CHD services across Wales. This includes putting forward the proposal for Phase II funding for ACHD in Wales and seeking to formally adopt the NHS England Service Standards for CHD.

Physiotherapy in Adult CHD

Physiotherapy is a vital component in the management of Congenital Heart Disease (CHD) throughout various stages of a patient's journey. The role currently includes chest physiotherapy for post-operative complications and rehabilitation to enable patients to get back to their normal activities.

Physical activity is important for everyone's health with research showing adults who have sedentary lifestyles are at least double the risk of serious disease and premature death. The benefits of physical activity include decreased blood pressure; improved weight management, psychological health and flexibility; it strengthens muscles, bones, joints and the immune system; reduces the risk of developing cancer and cardiovascular disease. Exercise also improves self-esteem, social skills and confidence in physical abilities.

Broadly speaking, CHD patients demonstrate lower levels of physical activity and decreased exercise tolerance than average. However, research has shown that appropriate exercise is safe for CHD patients to participate in and they too can gain health and social benefits from exercise. Most patients show willingness to exercise but are uncertain on how to exercise safely and the benefits.

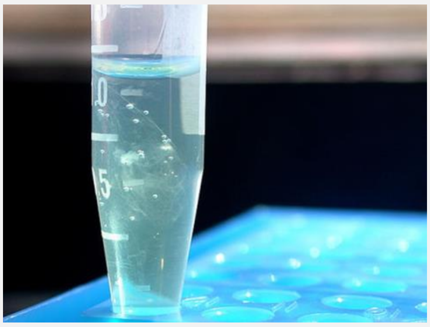
CHD patients should be provided with the education and support needed to increase their activity levels, including guidance on the signs and symptoms that are considered both normal and abnormal whilst exercising. Programmes should be tailored and safe for each patient reflecting their specific heart condition, individual anatomy and physiology. There are multifactorial considerations for clinicians when prescribing or advising CHD patients to exercise including:

- Intensity and duration of exercise
- Type of activity (static v's dynamic), level of participation (competitive or recreational), risk of injury
- Previous surgeries or catheter based procedures
- Presence of a cardiac device (pacemaker or ICD)
- Medication
- Other medical conditions such as hypermobility or learning difficulties.

Physiotherapy is more than just exercise prescription. It has an integral role in early mobilisation which is important to minimise functional decline and in the prevention of post-operative complications. It promotes lung function, manages airway secretions, reduces oxygen dependence and promotes safe and early discharge.

Small increases in physical activity can add up to big differences in your health. If you are a patient and wish to take up more exercise and reap the benefits, please discuss with your doctor at your next appointment.

Caroline Evans, Physiotherapist at the Bristol Heart Institute



West of England Genomic Medicine Centre

The West of England Genomic Medicine Centre (WEGMC) is one of a network of 13 regional Genomic Medicine Centres in England that have been set up within the NHS to help gain a better understanding of the genetic causes of cancer and rare disease.

The network is part of the Government's 100,000 Genomes Project, which aims to analyse 100,000 genomes from patients with cancer and rare diseases. The project also aims to transform ongoing care by implementing genomic medicine into the NHS. This will enable more accurate diagnosis of disease and develop novel treatments in the future that offer long-term benefit to NHS patients. 2,000 people from across the West of England have now been enrolled through the Genomic Medicine Centre.

Healthcare professionals can refer patients with a rare disease to the GM for consideration into the project.

For more information you can visit their website: http://www.wegmc.org/

A Mum's Story

By Amy Williams, mum to Josh.

We are from a small village called Nelson South Wales. Josh was diagnosed with hypoplastic right heart syndrome before birth (during my 20 week scan) by the doctors at the Heath hospital in Cardiff. I had weekly check-ups and it was planned for me to give birth at St Michael's Hospital. After an emergency section due to Josh's heart rate dipping, he was safely brought into the world on 2nd January 2011.

We spent a week at St Michael's and then went home to further follow-up appointments every Monday at the Heath. When Josh was 3 months old we went to the children's hospital in Bristol for his first open heart surgery, which was a stent, carried out by Mr Stoica. He spent 4 days in intensive care then transferred to ward 32, which is now Dolphin ward. After 2 weeks of fantastic care we was able to go back home with follow-up appointments every month.

In 2016 we returned to the children's hospital for keyhole surgery. This was only a 2 day stay. In May 2017 we were back again for Josh to have his final operation, a fontan procedure, carried out by Mr Parry. After 3 days in intensive care we were transferred to high dependency, then a week later to ward 32 where he spent the following 2 weeks. Our stay was 3 weeks in total, which is quite some time to be away from home.

The staff were truly amazing with Josh. His favourite nurse was Hanna on ward 32. His little face would light up when he saw her and he still talks about her now. Michele the play specialist was out of this world too. What a lovely lady! Josh got really frightened over having bloods taken so Michele brought a teddy into the room to show him what happens. It definitely helped.

All the staff were fantastic with him. Everything was explained to us in great detail and they did all they could for us. During the first week, when myself and Josh's step dad didn't have anywhere to stay, staff always found us a quiet space to stay in the unit and we were very grateful. For the last 2 weeks we were able to get a room at the Ronald McDonald which was a massive help to us. It was very comfortable, and having somewhere to freshen up and rest after a stressful and upsetting few weeks was wonderful!

Our experience over all was pretty scary but thanks to the amazing staff at the children's hospital, we got through it all. Josh is now 7 years old and like a different child - pink in colour, full of energy and confidence. I would never have thought I'd see him so happy. To all the staff at the children's hospital - THANK YOU!!

Blog Alert:

Zipper Club at 23

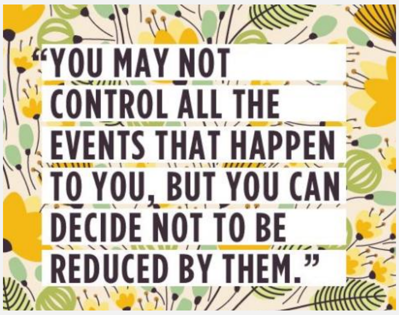
On her blog, Zipper Club at 23, Helen Doyle shares an honest insight into living with and overcoming chronic health problems in her early twenties.

Helen describes how her world was turned upside down through her congenital heart disease diagnosis and the requirement to have major heart surgery. She talks honestly about her fears, questions and concerns at that difficult time.

Fast forward to her latest blogs and we see Helen giving interviews about her experience and speaking at fundraising events, and even running the London Marathon – what an achievement!

This blog may be a useful resource for young people facing surgery. By sharing her experience, Helen hopes can help other people in similar positions.

The blog can be found at: https://zipperclubat23.wordpress.com/



"YOU MAY NOT CONTROL ALL THE EVENTS THAT HAPPEN TO YOU, BUT YOU CAN DECIDE NOT TO BE REDUCED BY THEM."

Research Update

Patients are being recruited to the INVITE study in both the paediatric and adult Level 1 Centres. This study offers an alternative to needing cardiopulmonary bypass (heart/lung machine) while having a pulmonary valve replacement. This technique is already used in some European countries but is fairly new in the UK. The aim of the study is to demonstrate how it performs compared to the traditional way of replacing the pulmonary valve.

The study involves teenagers and adults rather than younger children as the devices are only made in certain sizes. The research team will discuss the study with the patient (and families for younger patients) at the surgical clinic. If interested, they consent to take part. The nurses then randomise the patient to see which procedure the patient will have, as half will have the standard surgical procedure and half will have the implantable valve procedure. This is done so the team can look at differences between the two groups over time.

The patient and family will not know which procedure they have had until the end of follow up at 6 months. This is because part of the study involves asking patients how they have been during recovery and if they knew which procedure they had it might influence how they answer.

The PEACOCK study has already been done in adult patients and is now being undertaken in children having cardiac surgery requiring cardiopulmonary bypass. The aim of this study is to look at a hormone called cortisol and what happens to it during cardiac surgery, how it impacts the patient, and any implications for the future care of children having cardiac surgery.

In order to look at it in comparison to patients not having cardiopulmonary bypass the team will also include patients going for cardiac catheter as a control group (i.e. not having bypass). They will collect some small blood samples from patients to look at general blood results. To collect cortisol levels, they will place a very fine tube just below the skin in the abdomen while the patient is asleep. This connects up to a small pump and collection device which takes minute amounts of liquid from the cells under the skin every 10 minutes. The tube will stay in place for 24 hours. There is no follow up for patients in this study but the team will share the results of the study once available.

Another live study is THERMIC 3, which looks at the best way to look after paediatric patients who need to be put on a heart/lung machine during surgery, and whether it is better to give the mix of drugs that stop the heart to enable surgery (cardioplegia), warm or cold. 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

Meet the Paediatric Cardiac Physiology Team

The paediatric cardiac physiology team has grown to include 16 Cardiac and Assistant Cardiac Physiologists and they come from all over the world – including England, Wales, Canada, and Portugal.

As a department, they aim to provide an excellent service for patients and their families. The paediatric and fetal services have grown significantly in recent years. The team work with the local University, providing placements for future Cardiac Physiologists.

The team run an annual ‘Up the Pace’ event. This day is aimed at all paediatric patients, from anywhere in the region and beyond, with pacemakers and implantable cardioverter defibrillators, their families and friends.

Since 2014, they have a dedicated administrator who organises physiology appointments. If you need to change an appointment or you would like to contact a physiologist you can contact the team on 0117 342 8181.

Network Events

Part of the role of the network is to promote and deliver relevant events for professionals as well as for patients, families and charity partners.

On the website, there is a page on Training & Education for professionals. Below are some of the forthcoming events being advertised by the network:

- **ACHD Study Day**, 2nd October 2018, Bristol
- **The Bristol and Cardiff ACHD Echo Course,** 5th-6th November 2018, Bristol
- **Paediatric Cardiac Study Day for Community and Ward Nurses,** 20th November 2018, Bristol
- **British Congenital Cardiac Association Annual Meeting**, 14th-15th November 2018, Liverpool

Patients, families and charity partners can find out about events via the Get Involved section of the patients and families pages.

On 10th July 2018, the network held a **stakeholder day**, which brought together patients/family representatives, charity partners, commissioners and providers from across the CHD Network South Wales and South West. 53 people attended the event, which was an opportunity for the network team to update attendees on progress since the launch event in 2016, and for all present to discuss, debate and collaborate on network priorities for the coming year and beyond. People said:

"Just wanted to say what a great meeting it was yesterday and how inspiring it was. It was good to have MDT involvement too." *Pharmacist*

"I really enjoyed the event today, the group discussions were relevant…and I really enjoyed the afternoon format with multiple short topics." *Cardiology Consultant*

"An inspirational day with the @CHDNetworkSWSW yesterday in #Bristol. Thank you to everyone for your thoughts, experiences and vision for the future." *Charity Partner*

For more information on the discussions that took place, you can see the full report on the network website under Patient Engagement Events. Most people present said they would like the network team to run a stakeholder event every year, so keep an eye out for next year's date!

Sessions at the Stakeholder Day

During the CPD sessions for Clinicians in the afternoon of the stakeholder day, Adult CHD Clinical Nurse Specialists, Bethan Shiers and Sarah Finch, based at University Hospital of Wales in Cardiff, the Level 2 Centre, gave a talk on the use of the network palliative care toolkit in a local setting. The toolkit is available on the website in the Clinical Information section of the Professionals tab, under Palliative Care.

Network Lead Psychologist, Dr Vanessa Garratt, spoke about the new regional psychology service, which is now open to patients from all over South Wales and the South West, including face to face, skype or telephone appointments, as well as the huge range of online support for patients. This is available on the website under Getting Support. If you feel you would benefit from a referral to the service, please contact your consultant or Clinical Nurse Specialist. There is also information for clinicians on how to refer on the website under Patient Support.

National Patient Experience Survey for CHD

A set of online Patient Reported Experience Measure (PREMs) surveys for congenital heart disease has been launched nationally by NHS England. There are separate surveys for young children, parents/carers and teenagers/adults.

The aim of the surveys is to get the views of patients on their experiences of their local Level 1 Centres, for both inpatient and outpatient care. The different surveys ask about patients' experiences of admission, the ward, hospital facilities, staff, transition and discharge, and whether they would recommend the service to friends and families.

In the South Wales and South West network, the Level 1 Centre for adults is the Bristol Heart Institute and for children, the Bristol Royal Hospital for Children, both part of University Hospitals Bristol NHS Foundation Trust. The survey questions align with the standards set by NHS England for all hospitals providing specialist surgical congenital heart care.

The surveys take about 5 minutes to complete and can be found at: chdpatientsurvey.co.uk

Patients and families may have been asked by a doctor or nurse to complete a survey, or seen posters advertising the survey, or heard about it through charities or on social media. Patients and families can log on to the website at any time to share their feedback.

Level 1 Centres will receive a short report every three months on the responses to the survey and a more detailed report once a year. Patient feedback is an extremely important way for services to know if they are offering good patient experience and to highlight if improvements are needed.

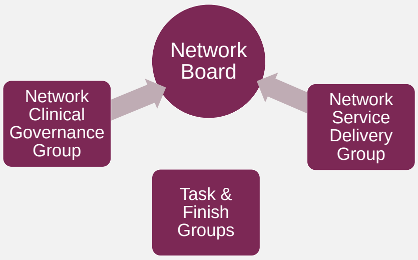
New Network Board Structure

At the March meeting of the South Wales and South West CHD Network Board, a proposal was put forward to change the structure of the network board meetings. The board is responsible for ensuring the network delivers its aims and agreed work plan.

Previously, four board meetings were held per year. Minutes of all board meetings can be found on the website, under Board Meetings in the 'About' section.

As the network has matured since its launch in 2016, it was felt the board meeting structure also needed to mature. In addition to the main network board, that will now occur twice a year, there will be two sub-groups of the board: the Clinical Governance Group and the Service Delivery Group. These groups will focus on delivering key clinical and service elements of the network's workplan for 2018-19 and beyond, and will also meet at least twice a year. There will also be time-bound task and finish groups for project work.

Clinicians of all professions, managers, charity partners and patient or family representatives can all have a role in the board structure. If you would like to get involved, please contact Caitlin.Moss@uhbristol.nhs.uk.


Network Board

Network Clinical Governance Group

Network Service Delivery Group

Task & Finish Groups

And Finally….

It wouldn’t be right to issue a summer 2018 newsletter without a mention of the Gromit Unleashed 2 trail, led by Bristol Children’s Hospital Charity *The Grand Appeal*. The trail sees Nick Park's Academy Award®-winning character Gromit return to Bristol for his second starring role in the award-winning charity's sculpture trails. But this time he's not alone; the loveable pooch will be joined by his pal Wallace and arch nemesis Feathers McGraw!

Until 2nd September, trail visitors can see over sixty sculptures, each individually designed and decorated by high-profile artists, designers, innovators and local talent, spread across the city and the surrounding areas area to raise money for the Bristol Royal Hospital for Children. Thornbury represents the most northerly point of the trail, with Avon Valley Adventure and Wildlife Park and Chew Valley marking the East and South boundaries respectively, and Weston-Super-Mare in the West.

The trail is the first in the world to feature three licensed characters; interactive sculptures and contactless donation technology thanks to support from a number of Bristol's leading institutions, pioneering technology companies and international engineering firms.

All funds raised will help The Grand Appeal to continue to support sick children, babies and their families who come from Bristol, and the whole of the South West and South Wales for lifesaving care at the Bristol Royal Hospital for Children (BRHC).

Come and join the
CARDIAC TEAM
on Thursday 9th August

JOIN US TO HELP CELEBRATE ALL OUR AMAZING PATIENTS, FAMILIES & STAFF!

WHERE: AT OUR GROMIT “THE HOWL” OUTSIDE THE RWA.

WHEN: 2- 4PM ON THE 9TH AUGUST 2018

BRING: YOURSELVES, FAMILY AND FRIENDS.

We will bring a camera, funky frames, lots of cake and a chance to hear one of our talented CNS`s sing with her choir.

Please come and help us celebrate everything Cardiac. We want to get photos of as many of you as possible, so put your creative heads on and bring along a picture frame just like Gromit’s to make the photos even more fun.

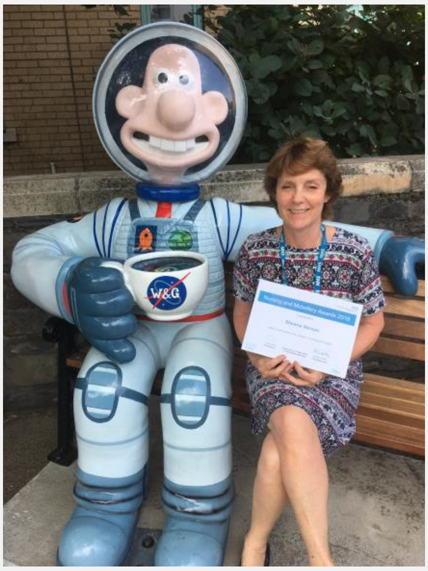
THE HOWL
raising money for Cardiology
at
Bristol Royal Hospital For Children

Gromit UNLEASHED 2

The paediatric cardiac team at the BRHC have their very own Gromit, and invite all their patients, their friends and families to join them in a celebration of the service on Thursday 9th August at the Royal West of England Academy, Clifton. For more info, including how to RSVP, please visit: https://www.swswchd.co.uk/en/page/patient-engagement-events

Network Lead Nurse

Our Network Lead Nurse, Sheena Vernon, received a high commendation in the category of Inspirational Leader in the University Hospitals Bristol Nursery and Midwifery Awards. She was nominated both for her role as an Adult Clinical Nurse Specialist in the Bristol Heart Institute and in her role as Network Lead Nurse - well done Sheena!



Thank you…

For taking the time to read this newsletter. If you have any stories or ideas you would like to share for the next edition, please contact Caitlin.Moss@uhbristol.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 Caitlin Moss, Network Manager on the address above or you can sign-up on the home page of the network website: www.swswchd.co.uk