

The Bristol Heart Institute is ten years old...2
In memory of Cathy...3
Introducing Xander...4
CHD network national peer review...5
Getting the right support?...6
Genetic and genomic services and education...7
Welcome to the network Dr Huxstep...8
3D printing in CHD research...9
Nutrition is paediatric cardiology...10
Heart families get together... 11
Transition from paediatrics to adult services... 12

Newsletter

News from the network team

Welcome to our Autumn Newsletter!

Reading through the many articles has provided us, and we hope you the reader, with a real sense of pride. This edition champions just a small selection of the recent progress we have experienced across our network, and includes a number of interesting articles and updates for our network staff, patients and families alike. With a particular focus on young people, we have lovely story from Evie talking about her journey from children's to adult's services, and signposts to the support and help available for young people with congenital heart disease (CHD).

There have also been a significant number of personnel changes across the whole network, not least the permanent appointment of Cat McElvaney who has been covering the role substantively since last October. We are also delighted to welcome Xander Cook, the new youth worker in the adult congenital heart service, to the network. We are already enjoying reading his often witty tweets and his informative Facebook updates. Xander will certainly be a great support and help for our young patients with CHD in the network.

In early summer, we were peer reviewed, as were all congenital heart services across the UK, by NHS England's quality surveillance team. The results of these reviews have been published and we are proud to report that the feedback was very positive for the network with a number of significant achievements identified. We have found it a useful exercise to enhance our work plan moving forward.

It is with great sadness that we end the introduction with a reflective note on the sad loss of our dear colleague Cathy Harrington around Easter of this year. Many of us were overwhelmed by the support shown by colleagues, patients & their families at her funeral. We are sure this helped her family come to terms with their grief. It was a beautiful day, the sun shone in the same way as she always did. May she forever rest in peace.

We would like to commend the efforts many members of the team who undertook a Mighty Hike in the Lake District for Macmillan in memory of Cathy and regret not being available to join them.

As ever we would like to thank all those who continue to collaborate, support and progress the work of the network to make it a success. We always welcome your input to the network, however small the contribution to improve the experience for patients and staff alike.

Meet Cat, our network manager



We are delighted to welcome Cat McElvaney to the team as the permanent CHD network manager for South Wales and the South West. Passionate about improving healthcare for patients and families, Cat joins the team with over 15 years' experience of improvement, change and programme management within the NHS. To find out more check out Cat's profile on our website (www.swswhcd.co.uk)

Key contacts

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

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

Network Manager: Cat McElvaney
Cat.McElvaney@uhbristol.nhs.uk

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

Support Manager: Morwenna Bugg
Morwenna.Bugg@uhbristol.nhs.uk

The Bristol Heart Institute is ten years old!

May 2019 marked the 10th anniversary of the Bristol Heart Institute (BHI)

The BHI, opened in 2009, was designed in partnership with patients, staff and the public and provides a dedicated service for people with heart conditions across the South West. This joint initiative between UH Bristol and the University of Bristol brought together all of the Trust's adult cardiac services under one roof. With advancement in technology, research and the effort of the staff, a lot has changed since 2009!



During the month, the Trust shared key milestones and personal stories from patients and staff from BHI. Find out more @UHBristolNHS on Facebook, Twitter and Instagram, using the hashtag #BHI10.

There was a wish tree in the atrium of the BHI throughout May where visitors and staff could leave notes to a loved one or a message of thanks.

Future plans for the BHI include opening a fifth catheter lab and to expand the research space at the BHI. It will be exciting to see what else the next ten years brings to the BHI!



159,000

outpatient appointments since 2009

1,500

heart operations per year

53,000

cardiology inpatients

5,975

patients treated through the catheterisation lab in 2018



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

Welcome to Dr Srinivas Narayan, lead consultant for paediatric cardiac imaging and Dr Ines Batista Gomes, locum consultant in fetal and paediatric cardiology, who joined the team at Bristol Royal Hospital for Children in June.

Welcome to Dr Chris Gillet, consultant paediatric cardiologist who has joined the paediatric team at University Hospital Wales, Cardiff.

Welcome also to Dr Katy Huxstep, paediatrician with expertise in cardiology, who starts in Truro in October.

Welcome to Xander Cooke, ACHD Youth Worker, based at the Bristol Heart Institute.

Welcome to Kat Peckitt, paediatric clinical psychologist in Taunton.

Goodbye to Nell Ellison, cardiac surgery psychologist in Bristol.

Network Dates for your Diary!

Key Network Meetings;

2019
28 November: Network Board meeting

2020
March tbc: Network Board meeting



In memory of Cathy

As many of you will already be aware our longstanding colleague, Cathy Harrington, sadly passed away at Easter following a short illness. In the days following her death there was an incredible outpour of gratitude from across the network for the support and kindness that Cathy showed to patients and their families during their time in our care.



Having worked as part of such a small, niche team for many years, the cardiac nurse specialists felt compelled to do something in her memory – to do something to help others, as she had always done. Cathy spoke fondly of the Macmillan team during her long stays in hospital; of the foot massages, the friendly faces and of the reassurance that they were always able to provide. So, with some trepidation, 11 brave members of the team signed up to the **Lake District Mighty Hike**. A marathon - 26 Miles of Lakeland walking, in one day: Lisa Patten, Jessica and John Hughes, Ella Houghton, Karl Limb, Sandra Dymond, Angie Hobbs, Catherine Armstrong, Nell Ellison, Jo and Scott Latham.

Saturday 13th July came, a cloudy start, but filled with good spirits. The day was not without blisters, aches and pains and a few tears, but together each member of the team crossed the finish line – for Cathy. We were generously supported and as such able to gift **£3,500 to Macmillan** which will go towards enabling them to continue the work that so benefitted our friend.

Cathy's spirit will always be a part of the Paediatric CNS team – her unique approach to patient care instilled in us all as we pick up the baton and try to be “**a bit more Cathy**”.



Introducing Xander

Hi, my name is Xander Cook. I am delighted to be Youth@Heart's new ACHD youth worker.



Background and Training

I am from Somerset and my interest in youth work started at the age of 13 when I set up an internet/gaming café in my home village. The café was hugely successful and ran for 10 years, stopping only when I left to pursue my youth work career at University, and technology changed - everyone has a console nowadays! I completed a BA (Hons) youth and community development degree at De Montfort University in Leicester between 2010 and 2013. Following this I got a job in Bristol working for the Bristol Youth Links contract, supporting young people on a 1:1 basis and running youth club sessions. I then moved into an educational role supporting learners pastorally who were working on an employability qualification with a local college, before returning to 1:1 support, when the college closed.

Interests

During my school days I felt I was on the fringes of groups rather than being in the centre of them – this fuelled my passion to provide spaces for young people who don't completely fit in, a place where they can really be themselves. I started volunteering for Over the Wall in 2007, a charity that provides residential camps to young people affected by health challenges. This inspired me to move my career into a health-based setting. I continue to volunteer for OTW to this day!

Current role and experience

I have just started my role as adult congenital heart disease (ACHD) youth worker. I work for Youth@Heart, a small charity based in Gloucester, supporting young people (16-24) with ACHD across the South West and South Wales, and I have an honorary contract with UH Bristol. Although I don't have any clinical experience I have been learning and reading about CHD from websites, the Clinical Nurse Specialist team, a book kindly borrowed from one of the ACHD psychologists called Open Hearts, and young people themselves who are living with ACHD. My plans for the next few months include writing to young people with CHD to introduce the youth worker role; finalising leaflets and posters identifying the support available and the referral criteria, to send out to peripheral clinics; planning activities in collaboration with young people; visiting some of the peripheral clinics, meeting and supporting young people on the wards and as outpatients.

Interests outside of work

In my spare time I am busy planning a 2020 wedding, listening to a wide range of music from rock, grunge and pop punk to reggae, dub and even to drum & bass, watching Netflix shows, going to the cinema or local gigs with my fiancée, playing my PS4 or fussing about the cat (Astra) that pretty much rules our house!

Do get in touch if you would like my help or to hear more about my job.

How Xander can help you:

- 1:1 support in the hospital
- Accompanying you to outpatient appointments
- Someone to talk to
- Linking you to other young people with CHD
- Helping you to share your knowledge and experiences with your peers
- Facilitating support in the community
- Liaising with educationalists and employees

How to contact Xander:

Email:

xander@youthatheart.co.uk
contactus@youthatheart.co.uk
xander.cook@uhbristol.nhs.uk

Phone:

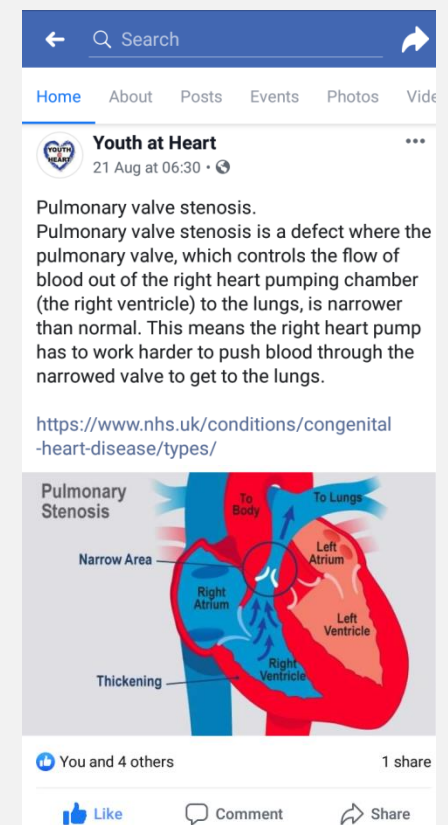
07832668907
01452 690830

Follow Xander on

Facebook:

Find Xander's posts on the Youth@Heart Facebook page:

www.facebook.com/atyouthheart



The screenshot shows a Facebook post from the page 'Youth at Heart' dated 21 Aug at 06:30. The post title is 'Pulmonary valve stenosis.' The text describes the condition as a defect where the pulmonary valve, which controls the flow of blood out of the right heart pumping chamber (the right ventricle) to the lungs, is narrower than normal. This means the right heart pump has to work harder to push blood through the narrowed valve to get to the lungs. A link is provided: <https://www.nhs.uk/conditions/congenital-heart-disease/types/>. Below the text is an anatomical diagram of the heart showing the right atrium, right ventricle, left atrium, and left ventricle. A red circle highlights the pulmonary valve area, labeled 'Narrow Area' and 'Thickening'. Arrows indicate blood flow: 'To Body' from the left ventricle and 'To Lungs' from the right ventricle. The post has 4 likes and 1 share.



CHD network national peer review

Over the past five months all CHD networks, level 1 and 2 centres across the county have been reviewed by a CHD peer group. This national CHD review, led by the NHS England's quality surveillance team, is a professional assessment of how the network, level 1 and level 2



centres are progressing against the delivery of the CHD standards. These standards, published in 2016, describe the way in which CHD services and the network are to be organised and run. The aim is to ensure all patients have access to high quality care and to ensure there are minimum differences between centres.

Preparing

In June 2016 the South Wales and South West CHD Network, the level 1 centres in Bristol (Bristol Royal Hospital for Children and the BHI) and the level 2 centre in Wales (Noah's Ark Hospital and University Hospital Wales) each had their own peer review. Prior to the review each team submitted a number of documents to evidence how they meet key CHD standards. This required a huge effort and organisation from each of the teams involved, which was commended by the peer review team - so well done to all the teams involved!



On the day

On the day of the peer review all the evidence submitted was discussed between the peer review team for outstanding queries. Representatives from the CHD team and the network patient representatives were then invited to attend a review team meeting. This meeting provided an opportunity for the review team and the CHD team to raise and respond to queries, to showcase some of examples of the improvements and the progress that has been made over the past three years since the standards were introduced. Thank you to all those who attended these meetings to support the network and centres!

The results!

Following the peer review, the network and centres involved have all received individual reports. These reports highlight good practice and significant achievements, any immediate risks (none identified), serious concerns and areas for improvement.

Significant Achievements/Good Practice

Over 30 areas identified as significant achievements. Highlights include;



- Cohesive team work and good collaborative working
- Development of clinical guidelines booklet
- ACHD journal club
- Network governance and network website
- Psychology service
- Patient and family involvement
- Reduction in waiting times for paediatric cardiac surgery
- Parallel planning for children
- Quarterly MDT meeting in Cardiff
- Transition nurse pathway and care plan.
- Positive patient engagement and feedback initiative including "Top and Pants"

Serious Concerns and Areas for improvement



Three serious concerns were highlighted for the level 1 centre. These concerns, around CNS staffing levels, transition in peripheral centres and surgical workload are well known risk assessed issues that the centres continue to address. A number of areas of improvement were identified for the network and the centres. Each centre will now pull together an action plan to address these areas. The action plans will be monitored via each Trust's existing governance processes and also via the network board.



Getting the right support?

Our psychology resources

We know that families have said that it's hard finding the right support at the times they need it. To help with this we have created a number of **useful resources** which can be found on our **website**: www.swswchd.co.uk



The resources on the website include:

- **Support digibooks** for babies and children, young people, parents, and adults. These interactive documents point you towards a range of sources of information and explain the different types of support available to you.
- **Wellbeing toolkits** for children, adults, parent/carers, and teenagers. The toolkits include information, ideas and strategies to help with questions and worries you may have.
- **Interactive patient pathways** for babies and children, teenagers/young people and adults which describe the different steps on your healthcare journey.

We now want to raise awareness of these and how to access other sources of support through a **Facebook campaign** called:



We will post a different question each month on local support group Facebook pages. We will also share these on the network twitter: [@chdnetworkswsw](https://twitter.com/chdnetworkswsw)



The questions will come from families themselves and will include a response signposting them to resources or places where they can access support.

Please look out for the posts, 'like' and share them.



If you would like to know more about the campaign please contact Vanessa Garratt, clinical psychologist, Vanessa.garratt@uhbristol.nhs.uk

Our psychology services

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



We are delighted to welcome **Katherine Peckitt, paediatric clinical psychologist at Musgrove Park Hospital, Taunton**. As part of developing their paediatric cardiac service, Kat has set up regular multidisciplinary team meetings for the team in order to have a forum to discuss any challenges and to develop a trauma-informed care approach. She offers three specialist cardiac appointments every week to children with heart conditions and their families. In the Bristol psychology team, they will continue to offer specialist care to all Taunton families having surgery, but Kat can help those families that are in need of psychological support locally.

In **Bristol** we are saying a sad goodbye to the cardiac surgery psychologist Nell and a warm welcome to Josie who brings a wealth of experience, knowledge and skills to our team. She will introduce herself in the next newsletter. In **Cardiff** recruitment is underway for a psychologist to join the paediatric service.

To help support the growing number of psychologists in the network we are offering a **Specialist Psychology training day** in spring 2020.

This will support any psychologists who may work with cardiac families and who would like an opportunity to develop their cardiac care skills. It is also an opportunity to become part of a growing network of cardiac psychologists in South Wales and the South West. If you are a psychologist and would like more information **please contact**: Vanessa Garratt, clinical psychologist, Vanessa.garratt@uhbristol.nhs.uk



Genetic and genomic services and education

by **Melanie Watson**, genetic counsellor and **Amanda Pichini**, lead genomics practitioner, West of England Genomic Medicine Centre

In the NHS, genetic testing has always been an integral part of the diagnostic journey for many patients and their families. The science of genetics has seen **significant advancements in technology** in the last few decades. It is now possible to read larger sections of DNA and in fact the whole of an individual's genome, and we continue to learn more about the implications of genomics in relation to health and disease as evidenced by initiatives such as the 100,000 genome project. **Genomic testing has had a significant impact in cardiology services**, and is increasingly done by large panels as this can provide more clarity on the genetic basis of a clinical condition and impact on the management of patients and their family members. Genomic tests including whole genome sequencing for certain indications are being phased in across clinical services in the NHS as part of genomic medicine services, where testing will be coordinated and delivered through a network of [seven genomic laboratory hubs](#).

This is a great time for us all to reflect on what that means for

healthcare professionals and patient groups across the NHS. [The genomics education programme in health education England](#) (GEP) has various **educational materials** that aim to update us all on current developments in genomic testing and how this impacts the healthcare workforce. There are a **broad range of resources** from infographics to more formal courses, organised by profession and by specialism.



Why not enrol on the next open access online learning course developed by the team at GEP '[Whole Genome Sequencing: Decoding the Language of Life and Health](#)' available via the Futurelearn platform to update your knowledge in a fun and interactive way.



It is also important that in our communities we have discussion around the implications of genomic testing and the repercussions for data storage and sharing. A recent review of participant experience in the 100,000 genomes project has just been published by [Genetic Alliance UK, commissioned by Genomics England](#) is a good place to start to see the views, experiences and concerns raised by this important group of participants and their families.

If you have any educational queries please direct them to [Melanie Watson](#), education lead for the South West Genomics Laboratory Hub at melanie.watson@nbt.nhs.uk



 Genomics	VS	 Genetics
<ul style="list-style-type: none"> ● The study of an organism's complete set of genetic information. ● The genome includes both genes (coding) and non-coding DNA. ● 'Genome': the complete genetic information of an organism. 		<ul style="list-style-type: none"> ● The study of heredity ● The study of the function and composition of single genes. ● 'Gene': specific sequence of DNA that codes for a functional molecule.

Are you aged 13-18 and have a heart condition?

Teen Heart is a free group you can join to meet other young people with similar experiences at events across the country.

Are you aged 18-30 and have a heart condition?

At **One Beat** events you can meet other young people like you, learn new skills and gain confidence.

Do you need help understanding your condition?



Looking for information about managing your lifestyle?

Find out more on the British Heart Foundation website:

www.bhf.org.uk/informationsupport/support/children-and-young-people

Lifestyle information for young people with single ventricle heart conditions

Visit the **youth section** of Little Heart Matters website to find information and get lifestyle advice: <https://www.lhm.org.uk/youth-zone/lifestyle-information/>

Find **articles** about:

Energy, tattoos and piercings, alcohol, keeping warm in winter, staying safe in the sun, and respecting your heart

Find **information booklets** about:

living with anticoagulation; Sports and exercise; travel and trips; information Filofax

Read **stories from other young people** with single ventricle conditions.



Little Hearts Matter
Supporting every step of the half a heart journey



Welcome to the network Dr Huxstep!

Dr Katy Huxstep, paediatrician with expertise in cardiology, is joining the paediatric team at Royal Cornwall Hospital in Truro in October 2019.



I am really excited to be joining the paediatric team at Truro and becoming part of the congenital heart disease network.

I love the balance and variety that general paediatrics gives me, but my true passion lies in paediatric cardiology.



I completed my general paediatric training in London in 2019. During my training I have undertaken two years of tertiary cardiology level working both at Evelina Children's Hospital in congenital and general cardiology, but also at Great Ormond Street in heart failure and heart transplantation.

In addition, I have experience in neonatal intensive care having worked at Homerton, and in paediatric intensive care working at Evelina in the PICU and for the South Thames Retrieval Service.

We are really excited to be moving to the South West and embracing the outdoors lifestyle. My daughter is super keen to get a dog and we both enjoy horse riding and fresh air.



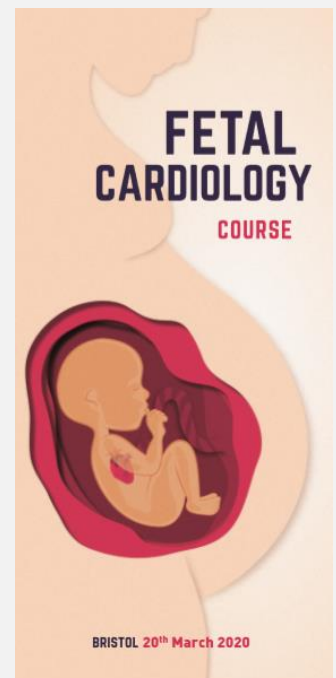
Conferences and training events

2019

- ACHD Study day, Bristol, 1 October
- Welsh paediatric cardiovascular Autumn meeting, Cardiff, 11 October
- Heart rhythm congress 2019, Birmingham, 6 October
- BSE Annual Meeting 2019, Birmingham, 11 October
- BCCA Annual Meeting 2019, Gateshead, 19-20 November

2020

- PEC study day, Exeter, 14 January
- Fetal cardiology course, Bristol, 20 March



For more information visit our training and education page:

www.swswhcd.co.uk/en/page/training-and-education



3D printing in CHD research

By Dr Andrew Shearn, 3D bio-printing research technician.

Three-dimensional (3D) printing has become a cost-effective method of creating bespoke parts and models. The technology has advanced such that it can now be used to produce 3D models of human organs using scans acquired during routine visits to the hospital. In our case we have begun to use this technique to create models of hearts, specifically those of patients with congenital heart disease (CHD). This initiative is supported by The Grand Appeal (Bristol Children's Hospital charity) and we have now set up the Bristol Bioprinting Unit at the Clinical Research and Imaging Centre (CRIC) at the University of Bristol.



CHD is an ideal discipline for 3D printing, as there are so many variations of congenital abnormalities, warranting a patient-specific approach. Applications range from teaching of students and junior doctors, to surgical planning and counselling. In our work, we principally create 3D models to give the cardiac surgeons or interventional cardiologists at the Bristol Royal Hospital for Children and the Bristol Royal Infirmary an additional tool with which to assess the case on which they are going to operate. Being able to hold a life-size model of the patient's heart in the clinician's hands can complement information derived from medical imaging. The surgeon or interventionist can, for example, practise aspects of the surgery or determine the best route to access a specific part of the heart. Having this facility in-house allows the surgeons to request models at short notice, while also allowing us to carry out research into the usefulness of the models. We also explore the use of models to improve communication between patient and doctor, or child patient, parents and doctor. This can be particularly useful in CHD as it is often challenging to explain the details of the case to a patient or a parent.

Finally, the 3D printing process can be extended to bioprinting. This is where layers of tissue can be produced on demand, using the same principal as 3D printing. This technique will allow us to create patient-specific tissues that do not suffer from the same problems of rejection as current tissues from other sources. These tissues will also be able to grow with the patient, potentially eliminating the need for additional surgery later in life.

If you are conducting any clinical or academic research in the network, please get in touch with Cat McElvaney, cat.mcelvaney@uhbristol.nhs.uk.

Clinical protocols

Did you know that you can access a wide range of clinical protocols via the CHD network website?

Go to the **clinical information** page under the professionals tab here:

www.swschd.co.uk/en/page/clinical-information

Clinical Information

A huge amount of collaborative work has happened recently to update and develop clinical protocol for clinicians within the network. These are already available via the document management service and will be uploaded onto the network website soon. A new dental pathway for adults has been finalised and the paediatric pathway is close to completion. Next steps will involve implementation of these pathways across the network.

Looking back

Want to know what the network and centres have been up to in **2018/19?** -The **SWSW CHD annual report** has just been published! Check it out by clicking on our website www.swschd.nhs.uk



Annual Report

2018/19



Nutrition in paediatric cardiology

By **Rebecca Newbury, paediatric dietitian**

For children born with Congenital Heart Disease (CHD), nutritional support is an important component of their treatment.



Infants with CHD often have **higher nutritional requirements** due to greater energy expenditure resulting from an increased effort for breathing. Delivering adequate nutrition can be difficult for a number of reasons e.g. fluid restrictions, feeding intolerance and poor blood supply to the digestive tract. Often infants need to reach a 'target weight' to allow them to receive vital heart surgery, placing added pressure on parents or carers to achieve weight gain.

Many infants require the support of **nasogastric (NG) tube feeding** if they are unable to take enough feed to promote growth. Of

And ten infants will take small amounts orally but tire quickly, and this is where NG tubes are used to support oral feeding. High energy infant formulas can be used to replace standard infant formulas (or used in addition to expressed breast milk if available) to provide more nutrition in less volume. This can be particularly useful for infants struggling to tolerate large volumes of feed or on tight fluid restrictions. Although NG tube feeding is essential for a large number of children with CHD, dependency on NG tube support can be a significant complication in infants, risking delaying their oral development skills. Close working with the dietitian and speech & language therapist post operatively improves the transition from tube feeding to oral diet.

In a small number of children receiving heart surgery, the lymphatic thoracic duct may be damaged (Chylothorax), causing the milky fluid (Chyle) to leak into the pleural space which can cause breathing difficulties. Alongside medical management, the child will require a 'fat free' diet. The diet replaces the long chain triglyceride (LCT) fats eaten in the child's normal diet with medium chain triglyceride (MCT) fats for 6-8 weeks. This diet can be very challenging for families of older infants and children therefore support from a dietitian to provide a variety of recipes and supplements to prevent weight loss is essential.

As children get older, it is important to remember that the majority of children with CHD will likely transition to **normal age appropriate dietary recommendations**.



For more information on making the right food choices, visit:
<https://www.bhf.org.uk/information-support/support/healthy-living/healthy-eating>

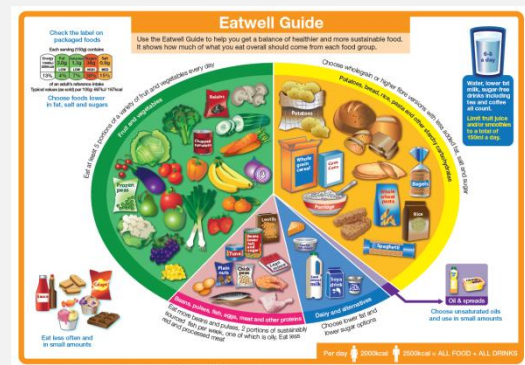
Tips for healthy eating

Visit the British Heart Foundation website for more information on healthy eating:
www.bhf.org.uk/information-support/support/healthy-living/healthy-eating

Try to eat:

-  • Plenty of **fruit and vegetables**. Aim for **5 a day**.
-  • **Plenty of starchy foods** such as bread, rice, potatoes and pasta. Choose wholegrain varieties where possible.
-  • **Some milk and dairy** products
-  • Some meat, fish, eggs, beans and other non-dairy sources of **protein**
-  • A small amount of foods and drinks high in **fats** and/or **sugar**.

Read about the **Eatwell guide** on the British Heart Foundation website:
www.bhf.org.uk/information-support/support/healthy-living/healthy-eating/healthy-eating-toolkit/eatwell-plate





Heart Families get together

By Kelly Cornish, Founder of Heart Heroes



On July 6 2019, Heart Heroes, Heart families South West and Heart Children Gloucestershire all came together for a heart family day out at The Noah's Ark Farm and Zoo in Bristol. The trip was part-funded by The Grand Appeal and Heart Heroes.

We had 65 adults/children attend and it was great to see everyone having fun. Heart Heroes set up a base so the families could come and go as they wished especially as it was a very sunny day. Everyone met back up at the same time for lunch and each heart child received an ice lolly.

We hope to make this an annual event.

Reviews from two Heart parents:

'Thank you so much for organising the day out, we had a lovely day. I still feel more wobbly than I had realised about my daughter's heart, and being able to meet other people yesterday was really wonderful. Also just to have a lovely day out and see other families, it still feels like a whole new part of our lives and I really appreciate your support yesterday. I'm sure it was a lot of work but I wanted you to know how much I appreciated it and how lovely it was to meet you.'

'As a parent of a heart hero, days out are sometimes often quite isolating and lonely and it's lovely to be part of the group. My kids had the most amazing day making lots of new friends. Having a base was great as my heart warrior tires easily so we were able to sit relax and rest for a bit. Having an opportunity to chat with other heart mums is so important and we were able to catch up with some families we haven't seen for some time and a couple of families we have met through the hospital. Thank you so much for providing us with this amazing opportunity!'

2019 local charity events

To find out about more charity events visit the network website page to find links to charities across the network:

www.swswhcd.co.uk/en/page/charities



Relax kids family workshop

→ September/October

Razzamatat theatre schools classes

→ September - December

Heart Heroes Christmas party

→ 15th December



Quiz night

→ 4 October

Christmas fair weekend

→ 30 November/1 December

Christmas wreath making workshop

→ 9 December

Christmas table decorations workshop

→ 17 December





Transition from paediatrics to adult services

By Evie Carlin

'I was born with a congenital heart condition and have always been under the care of the University Hospital Wales. For 18 years I was under the care of Dr Wilson and in the summer of 2019, I attended the joint clinic to move from paediatric care to adult care.



The joint clinic, despite the lack of an underwater theme (as they do in the paediatric unit!) made the transition smooth and easy. It wasn't in the slightest intimidating, as I thought an adult clinic could be. I felt it was very helpful to see the same familiar faces that I remembered from the paediatric unit which made everything seem a lot less daunting.

The fact that everything about my heart condition was explained thoroughly helped put me at ease and worry less about what could have been a daunting situation. Also, everything was discussed in terms I understood, without being patronising.

I felt very supported throughout the appointment with all of the staff being very kind and explaining what they were doing and why. There was a personal and friendly feel as all the nurses smiled and said 'hello' as they passed through the waiting room. I felt as though I was a person and not a number. All the staff were patient and happily answered any questions or concerns I had. Although I was accompanied by my mum this time, I feel as though I would have the confidence to go on my own next time.

Overall, I felt joint clinic was extremely helpful and has eased a lot of worries and questions I had about my condition. Although it was an adult clinic, I did not feel out of place being the youngest there.'

Visit the CHD network website to access a **toolkit** which will help explain what will happen during transition from paediatric to adult services here: www.swswchd.co.uk/en/page/toolkits-for-teenagers



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 **March 2020**, please contact cat.mcelvaney@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 Cat McElvaney, network manager on the address above, or you can sign-up on the home page of the network website: www.swswchd.co.uk