Congenital Heart Disease Network
South Wales and South West

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December 2016
Issue 1

Congenital Heart Disease Network Newsletter

THE NEW CHD NETWORK

Welcome to the first issue of the Congenital Heart Disease Network Newsletter. We will use this quarterly newsletter to communicate with patients, families and clinicians involved with congenital heart disease services in the South West and South Wales. To make sure you receive future copies please subscribe by dropping us an email here.

The South West South Wales CHD Network was formed in April 2016 in order to bring together health professionals, patients and families involved with congenital heart disease services.

Involving patients, families, clinicians and other interested groups from across the region is fundamental to our success. You can read more about the network team and network board later in this issue. If you want to get involved in shaping CHD services please get in touch via the contacts listed on the right of this page.

THE NETWORK VISION

Our vision is to be a Network whereby:

- Patients have equitable access to services regardless of geography
- Care is provided seamlessly across the Network and its various stages of transition (between locations, services and where there are co-morbidities)
- High quality care is delivered and participating centres meet national standards of CHD care
- The provision of high quality information for patients, families, staff and commissioners is supported
- There is a strong and collective voice for Network stakeholders
- There is a strong culture of collaboration and action to continually improve services

OUR OBJECTIVES

- To provide strategic direction for CHD care across South Wales and the South West
- To monitor and drive improvements in quality of care
- To support the delivery of equitable, timely access for patients
- To support improvements in patient and family experience
- To support the education, training and development of the workforce within the Network
- To be a central point of information and communication for Network stakeholders
- To ensure it can demonstrate the value of the Network and its activities

ACCESS THIS NEWSLETTER ONLINE: http://tinyurl.com/hmo5a8h

INSIDE THIS ISSUE

KEY CONTACTS

Clinical Director: Dr Andrew Tometzki

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Lead Nurse: Sheena Vernon

Sheena.Vernon@UHBristol.nhs.uk

Network Manager: James Dunn

James.Dunn2@UHBristol.nhs.uk

Network Administrator: Rachel Benefield

Rachel.Benefield@UHBristol.nhs.uk

PATIENTS AT THE CENTRE OF OUR WORK

One of the key aims of the network is to ensure patients can tell us what is working well, what they would like to see improved, and how they can help us do that.

On our Network Board (see page 5) we have 5 patient and support group representatives:

- Hussien Amiri—an adult congenital patient from Cardiff, who is also a Governor at University Hospitals Bristol
- Kevin Mashford—an adult congenital patient from Bristol with experience running his own business, fundraising and developing an app for patients with CHD
- Liza Packer—an adult congenital patient from Truro
- Sally Parker and Nicola Morris—parents of children with CHD. They run the Heart Families South West support group

These board members ensure that patients' views are heard at the board meeting as well as helping to advise on actions that will improve services for patients.

CHD centres should allow patients to participate in decision-making at every stage in their care

HOW PATIENTS AND SERVICE USERS CAN GET INVOVLED

At our listening events patients have told us that they want a range of different ways to engage with us depending on how much time they have or how interested they are in a particular topic. As a result, we have created a menu of options of how you can contact us. You can see this menu here. You may simply want to give us some feedback on your experience or you may wish to get involved in a group designing a new service improvement. Here are some of the ways you can get involved:

- Contact us directly by email
- Sign up to receive our newsletters and emails
- Come to an engagement event near you. We will be holding several events around the region.
- Speak to us in clinic. The network team will be visiting clinics around the region specifically to hear the views of patients
- Join an online reference group to input on a particular topic. We will have a number of areas where we want your input. The first is likely to be helping us design our website—what information you want to see and in what format
- Get involved in the work in Bristol Royal Hospital for Children in response to the Independent Review
- Feed back directly to your local clinician who will then be able to pass your views on to the network team

To get involved in any of these ways, or if you have another way you would like to give us your view please contact us.

SUPPORT GROUP FOCUS: HEART FAMILIES SOUTH WEST

Heart Families South West exists to give parents/carers and close family members the opportunity to offer support to each other with the day to day challenges of having a child with a heart condition.

The group was initially set up as Exeter Heart Families by Sally Parker in 2012 and has grown from a few families in Devon to nearly 450 members. The group was renamed Heart Families South West in 2014 to reflect its membership across the clinical network, and is managed by a small admin team of Heart Mums.

We are a welcoming and sociable network of families who understand the challenges of having a child with a CHD, so can offer support and understanding during the highs and lows of their journey. We offer a closed Facebook group which provides a secure environment for members to talk openly about the challenges and worries they are facing. In addition we have regular Summer and Christmas parties to give families the opportunity to come together socially away from hospital.

We have asked our members what they liked about Heart Families South West and words/phrases such as ‘Supportive’, ‘Empathetic’, ‘Understanding’, ‘Able to sign post to qualified professionals’, ‘Non-judgemental’, ‘Feel part of a family’, ‘Makes you feel you are not alone, and ‘Heart Families South West is a pillar of strength’ are commonly used.

www.facebook.com/groups/HeartFamiliesSouthWest/

www.heartfamilies.org.uk

> *“We are a welcoming and sociable network of families who understand the challenges of having a child with a CHD”*

SUPPORT GROUPS

South West Children’s Heart Circle
A charity aiming to help children and their families, before, during and after cardiac surgery in the Bristol Royal Children's Hospital

Heart Families South West
A support group for children and families of children who have a heart condition

Somerville Foundation
A national charity working with patients with CHD, providing practical and emotional support, and enabling them to take control of their lives and manage their own heart condition.

Little Hearts Matter
A national charity offering help to anyone affected by the diagnosis of single ventricle heart condition

LISTEN TO GEORGE AND EAT WELL

This is George, one of the patients who was recently on ward 32, the cardiac ward at Bristol Royal Hospital for Children. You can see he had lots of fun while on the ward making a healthy eating vending machine and posters for healthy eating and to stop smoking.

The staff on ward 32 encourage everyone to get involved in activities to make their stay more comfortable. The play centre has a huge range of toys and activities including a garden space and is open every day. Most wards have their own play rooms where you will find a dedicated play specialist who is in charge of FUN! We also have a School room so that patients can stay on top of their school work if they are well enough.

If you want to find out more about what it is like on ward 32 at Bristol Royal Hospital for Children you can visit their website.

THE INDEPENDENT REVIEW OF CHILDREN'S CARDIAC SERVICES IN BRISTOL

The Independent Review of children's cardiac services in Bristol was triggered by the concerns of a number of families about the treatment and care received by their children. The Review was set up by the Medical Director of NHS England to carry out a thorough review of children's cardiac services at the hospital and its outreach clinics, to learn lessons and to contribute to the development of national standards of care. An independent audit and review of the medical records of a sample of children who were cared for in Bristol cardiac services between January 2012 and December 2014 has also been conducted by the Care Quality Commission. Both these reports can be accessed here.

Since the publication of these reports UH Bristol has been working hard on implementing the recommendations of these reports. A detailed action plan has been developed by staff to deliver these recommendations and a trust wide steering group, chaired by Carolyn Mills, Chief Nurse, has been set up to oversee and monitor progress, reporting to the Trust Board on a monthly basis. To find out more please click here.

Parents have played an important role in bringing about improvements in how we deliver care and we are very keen to have families involved in this work. We have already been engaging with families about implementing the recommendations including setting up a virtual parent's reference group for this work and having parent representatives on the steering group.

You can find out more about how to get involved in this work here

Patients and parents have played an important role in bringing about improvements in how we deliver care

TEST OUR NEW WEB PAGES FOR THE INDEPENDENT REVIEW

To support the work that Bristol Royal Hospital for Children is currently undertaking as part of the Cardiac Review, they are updating the dedicated web pages and would be grateful if you would be able to look at the draft information and let them know if there is anything that you feel does not make sense or is missing that should be included. You can see the information here.

The pages are to meet the information needs of parents and professionals so we have tried to take a middle ground in terms of tone. They are also only about the Review – there will be a link to the Bristol Children's Hospital general pages which cover detailed service information for patient and families, rather than duplicating the content within the same site.

Please let Lisa Smith (LIAISE Family Support Team Manager) know if there are any changes you would like to suggest or areas you feel we should add. We will be seeking approval from the Cardiac Review Steering Group to make this update on Tuesday 6th December so any comments received prior to this date will be incorporated for their review. However, if you are unable to review the content within this time, you are welcome to comment at a later date as we will be developing the pages to keep pace with the project.

If you have any queries, please do not hesitate to contact me on 0117 342 7445 or email me with your questions (Lisa.Smith2@UHBristol.nhs.uk).

NETWORK FOCUS: WELCOME TO OUR NEW CHAIRMAN

We are pleased to announced that Dr David Mabin was appointed to be the Chairman of the CHD Network Board.

Dr Mabin is a consultant paediatrician with expertise in cardiology who works in Royal Devon and Exeter Hospital. He has over 20 years' experience as a consultant, including 5 years as a clinical lead. He has also been a university medical school sub dean and, more recently, an associate dean, involved in delivering and assuring the standard of undergraduate education in Exeter. He has chaired committees in both the medical school and NHS including the PECSIG group (Paediatricians with Expertise in Cardiology Special Interest Group).

Dr Mabin has been involved in the development of clinical guidelines relating to congenital heart disease standards and has helped define the syllabus for the RCPCH SpIn module in paediatric cardiology. He has been involved in peer review of CHD services and recognises the challenges faced by CHD networks. He is also a keen patient advocate, acutely aware of the importance of involving patients and families in developing clinical services.

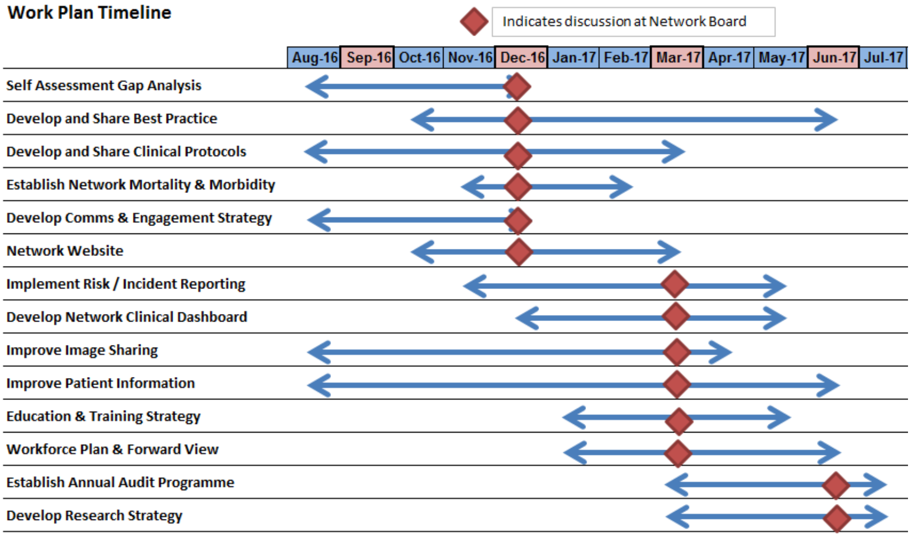
THE NETWORK BOARD

The Network Board is responsible for ensuring that the network sets out clear plans to meet its objectives and that it delivers against these plans. The Board has representatives from across South Wales and the South West, including: patient and support group representatives, consultants, nurses, service managers and commissioners.

We had our first network board meeting on 29th September where we agreed the priorities and work plan for the coming year. A summary of the work plan is shown below.

If you are interested in providing input or supporting a particular area of work please contact us. We are particularly keen to hear from patients or families who wish to influence the way CHD services are run in the region.

You can read the minutes of our first board meeting here



THE NETWORK TEAM

Sheena Vernon, Lead Nurse

James Dunn, Network Manager

Dr Andrew Tometzki, Clinical Director

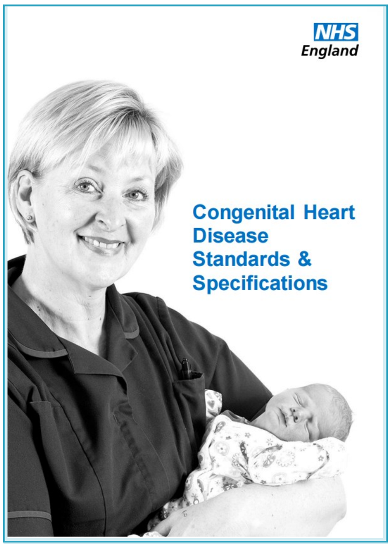
Rachel Benefield, Network Administrator

WORKING TO MEET THE CHD STANDARDS

In May 2016 NHS England published comprehensive standards for CHD services. There are over 200 standards across 13 domains—The network approach; Staffing and skills; Facilities; Interdependencies; Training and education; Organisation, governance and audit; Research; Communication with patients; Transition; Pregnancy and contraception; Foetal diagnosis; Palliative care and bereavement; and Dental.

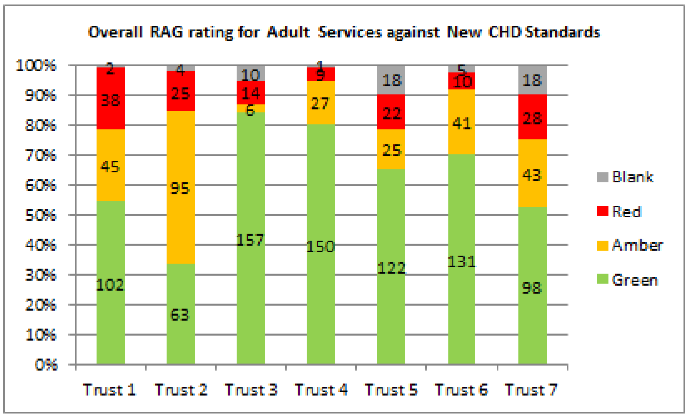
These standards represent best practice for CHD services and as such are designed to stretch providers to deliver the best possible care. It is likely that not all services will meet all the standards immediately, but there is an expectation that providers will work towards meeting all of standards.

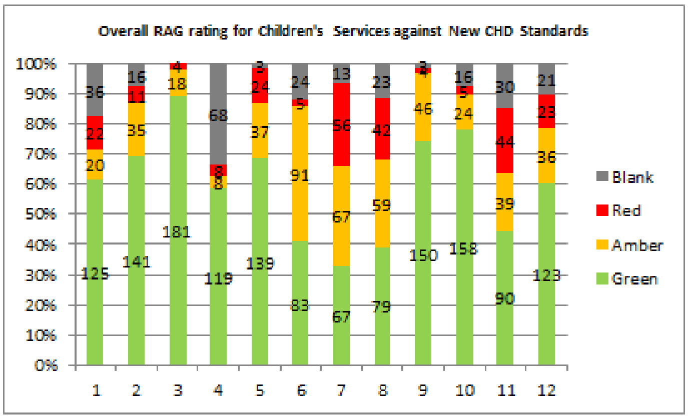
One of the core aims of the CHD Network is to ensure that providers of care are striving to achieve these standards.



Providers in the South West and South Wales region are already meeting over 60% of the standards

SELF-ASSESSMENT AGAINST THE CHD STANDARDS





All hospitals within the network have been asked to self- assess against the standards, grading themselves red, amber or green against each. The charts above show where each of the hospitals in the network have scored themselves against the standards. These are shown here anonymously until we have a chance to meet with each hospital team to understand their assessment and where the priorities are. In time we will publish data on how we are doing on our forthcoming network website. The network board will use this to develop the priorities for the network team for the coming year.

Some of the priority areas around which we have already begun work are:

- Providing clear, consistent information for patients and families
- Supporting clinicians with time for CPD and attending MDTs
- Improving links between centres for image sharing and communication
- Developing clinical protocols

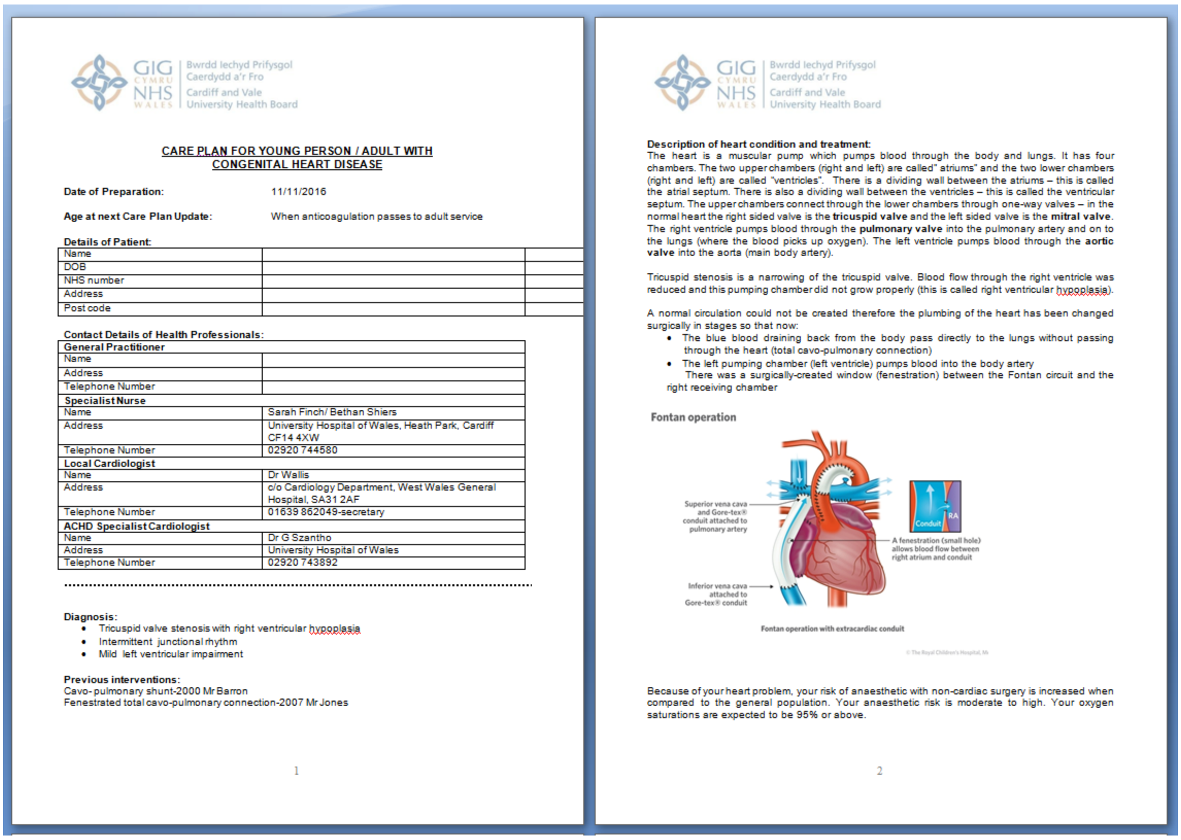
DEVELOPING TRANSITION SERVICES IN WALES

In April this year Cardiff held their first transition clinic at University Hospital of Wales where young people begin the journey from children's to adult's services. Since then they have held transition clinics in every local health board in South Wales.

Transition has been identified as a vulnerable time for young people and their families as they move from a familiar health service accessed from birth to an adult service which is unfamiliar and structured differently. Many young people become "lost to follow up" as they fail to engage with their new service. Historically in Wales there was a Paediatric Transition Nurse Specialist but no Adult Congenital Nurse Specialist (ACHD Nurse) or a lead Adult Congenital Cardiology Consultant. Adult clinics were busy and could therefore feel impersonal and there was no formal transition clinic.

All that has changed following substantial investment in the ACHD service, allowing the appointment of a lead consultant in ACHD and two specialist nurses. Transition clinics now run in each of the local health boards. In these clinics adolescents are seen by the Paediatric and ACHD Consultant and medical issues discussed. The Transition Specialist Nurse and ACHD nurses then meet the adolescent to discuss lifestyle issues including diet, exercise, smoking, alcohol intake, reproductive health, travel, driving and what to look out for in an emergency. Every young person has an individualised transition care plan made for them as a hard copy. Copies are also kept on the database, sent to their GP and filed in their medical notes. See the example care plan below.

All very interesting, but are the clinics useful I hear you ask. In short the answer is – Yes! The young people feel they have now got a new team who understand their previous medical treatments but just as important also have a good understanding of their future plans and what is important to them. They are able to put a face to the name of their point of contact in the ACHD service-a seamless continuation of the point of contact offered by paediatrics.



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CARE PLAN FOR YOUNG PERSON / ADULT WITH CONGENITAL HEART DISEASE

Date of Preparation: 11/11/2016

Age at next Care Plan Update: When anticoagulation passes to adult service

Details of Patient:

Name		
DOB		
NHS number		
Address		
Post code		

Contact Details of Health Professionals:

General Practitioner	
Name	
Address	
Telephone Number	
Specialist Nurse	
Name	Sarah Finch/ Bethan Shiers
Address	University Hospital of Wales, Heath Park, Cardiff CF14 4XW
Telephone Number	02920 744580
Local Cardiologist	
Name	Dr Wallis
Address	c/o Cardiology Department, West Wales General Hospital, SA31 2AF
Telephone Number	01639 862049-secretary
ACHD Specialist Cardiologist	
Name	Dr G Szantho
Address	University Hospital of Wales
Telephone Number	02920 743892

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Diagnosis:

- Tricuspid valve stenosis with right ventricular hypoplasia
- Intermittent junctional rhythm
- Mild left ventricular impairment

Previous interventions:
Cavo- pulmonary shunt-2000 Mr Barron
Fenestrated total cavo-pulmonary connection-2007 Mr Jones

1

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Description of heart condition and treatment:
The heart is a muscular pump which pumps blood through the body and lungs. It has four chambers. The two upper chambers (right and left) are called" atriums" and the two lower chambers (right and left) are called "ventricles". There is a dividing wall between the atriums – this is called the atrial septum. There is also a dividing wall between the ventricles – this is called the ventricular septum. The upper chambers connect through the lower chambers through one-way valves – in the normal heart the right sided valve is the **tricuspid valve** and the left sided valve is the **mitral valve**. The right ventricle pumps blood through the **pulmonary valve** into the pulmonary artery and on to the lungs (where the blood picks up oxygen). The left ventricle pumps blood through the **aortic valve** into the aorta (main body artery).

Tricuspid stenosis is a narrowing of the tricuspid valve. Blood flow through the right ventricle was reduced and this pumping chamber did not grow properly (this is called right ventricular hypoplasia).

A normal circulation could not be created therefore the plumbing of the heart has been changed surgically in stages so that now:

- The blue blood draining back from the body pass directly to the lungs without passing through the heart (total cavo-pulmonary connection)
- The left pumping chamber (left ventricle) pumps blood into the body artery

There was a surgically-created window (fenestration) between the Fontan circuit and the right receiving chamber

Fontan operation

Fontan operation with extracardiac conduit

© The Royal Children's Hospital, Mi

Because of your heart problem, your risk of anaesthetic with non-cardiac surgery is increased when compared to the general population. Your anaesthetic risk is moderate to high. Your oxygen saturations are expected to be 95% or above.

2

An example care plan from the transition clinic

MEET THE PAEDIATRIC CARDIAC RESEARCH TEAM

Since 2011 there has been a cardiac research nurse working at the Bristol Children's Hospital. The idea was to capture all research activity involving cardiac patients to ensure a unified approach.

Today there is one full time Research Sister and 4 part time Senior Research Nurses. We cover both Cardiology and Cardiac Surgery studies.

We work collaboratively with all clinical areas and clinicians to provide best practice in any research study involving cardiac patients.

Our role is to screen for patients who may be eligible for a study, give them information about the study in a way they can understand, and consent them to the trial if they feel it is right for them. We also collect data, organise appointments and tests and many more tasks we won't bore you with.

Our main role though as we see it is to give our patients and families a good experience of being approached for research, whether they take part or not. We always say that it's our job to give information and answer questions so that the family can make the decision that's right for them.

Karen Sheehan (Sister), Kathy Selway, Carrie Cherrington, Nicola Blackshaw & Julie Madden

PAEDIATRIC CARDIAC RESEARCH UPDATE

The paediatric cardiac research team currently has 12 studies in different stages of set up, recruitment, follow up and close down. Our studies which are currently recruiting are

INCIDENCE/IMPACT study which looks at complications after cardiac surgery in children and how those complications impact on the child and family after discharge from hospital.

INVITE which looks at standard surgical replacement of Pulmonary valves versus injectable valves in teenagers and adults.

RVENCH which is aiming to understand why some patients tolerate high right ventricle pressures and some don't.

STEM CELL which is developing techniques to be able to grow a patient's own tissue for use in cardiac surgery in the future.

They are also in the follow up stage for a national drugs trial looking at aortic root growth in Marfan's patients. It is one of 10 international studies looking at this issue and Bristol was the highest recruiter for the study thanks to the generosity of our patients.

Studies cover all surgical patients coming to Bristol Children's Hospital from all over the South West and Wales

The research team are also heavily involved in developing PPI (public & patient involvement) in research. This means anything from helping decide what areas of practice need to be looked at in research, to helping design information, giving feedback on research protocols and study design. They are working with Noreen Hopewell-Kelly to set up patient and parent groups to help take this forward. They recently held a competition at a Bristol primary school to design a logo for all our young person's paperwork and website. This is just a start and they have invited families around the South West and Wales to get involved.

For more information please contact the team on 0117 342 8889

ALERT FOR CLINICIANS: LIVE FLU VACCINE

The live attenuated intranasal vaccine is contraindicated in children and adolescents who are taking aspirin. Many clinicians and nursing colleagues may not be aware of this precaution. It is deemed to be a theoretical risk only, but this drives policy.

"The national advice in chapter 19 of the Green Book, referring to the live attenuated intranasal flu vaccine (LAIV), reads: It is contraindicated in children and adolescents receiving salicylate therapy (other than for topical treatment of localised conditions) because of the association of Reye's syndrome with salicylates and wild-type influenza infection as described in the SPC for Fluenz Tetra®"

These patients should be offered injectable inactivated vaccine.

Patients who have questions about this should contact their GP, cardiac liaison nurse or cardiologist.

FEEDBACK

If you have ideas for content please let us know.

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