

SPECIAL
POINTS
OF INTER-
EST:

- Pharmacy - in this issue find out all about diuretics
- What to do if your child has Bronchiolitis
- Dates for your diary
- Introductions from both the Research and Nurse Education teams!

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Cardiac News

ISSUE 3, AUT/WINT 2015

Pharmacy Hot Spot: Diuretics

You may have heard the term diuretic mentioned as part of your child's medication. A diuretic encourages the body to produce more urine by making the kidneys filter more water and salts.

It is used in patients with heart conditions because if there is too much fluid in the body then the heart will need to work harder to pump the blood around the body. By taking a diuretic the amount of fluid in the body can be reduced to reduce the pressure put on the heart and also lower blood pressure.

Two of the most common diuretics used are furosemide and spironolactone. Furosemide is a strong diuretic and spironolactone is a weaker diuretic. Both can

be taken once, twice, three or four times a day depending on the doctor's decision



and are often paired and taken together.

The reason for this is furosemide reduces potassium in the body and spironolactone can stop this.

Times when they are not given together may be because the patient is taking another medicine that affects the potassium level (such as captopril) or be-

cause blood tests show there is enough potassium in the body.

Both furosemide and spironolactone come as tablets or in liquid form. At Bristol Children's we supply the liquid as a 50mg/5ml strength and it is important to ensure that the same is supplied from your community pharmacy to avoid any errors. You can prevent changes in the strength supplied by showing the bottles we have supplied to your local GP or pharmacy.

Tips: As both furosemide and spironolactone increase the production of urine, in older children they may want to take their doses earlier in the day and not near bed time to avoid waking up at night for the toilet.

Fond farewells

The CNS team are about to undergo another change:

It is with great sadness that our colleague **Debbie Riddiford** is due to retire in December.

Many of you will have met Debbie on many occasions during her time with the

cardiac team both in an inpatient capacity and more recently as a key member of the surgical and pre-assessment team.

We thank you for all your hard work, dedication, and friendship, and wish you all the very best for your retirement Deb!



We also say goodbye to **Laura Hamblin**, our team administrator who is off to start a new position in Cardiff. We wish you every success in your new job Laura!

Cheers!

Cardiac Psychology Service



Nell and Vanessa
can be contacted on:
(0117) 342 8168

CARDIAC NEWS

Clinical psychology in Paediatric Cardiology: what do we do?

As the clinical psychology service has recently expanded, I thought writing a little about the kinds of things we support children and their families with might be helpful. Below are some of the things we often support people with, but this is by no means a complete list so please get in contact with us if you feel unsure about whether psychology could be helpful and would like to discuss this further.

Helping children and families through the experience of cardiac surgery. This can involve:

Supporting and preparing children if they are anxious about procedures such as blood tests, cannulas, and the surgery itself.

Helping parents find ways to talk to their children about surgery.

Supporting children after surgery (for example, if there are any anxieties about getting back to school or engaging in other activities, worries about

having a scar, and getting use to any new medications or treatments like Warfarin).

Supporting parents and siblings with their own feelings about surgery.

Supporting children and their families with the experience of being in hospital, including Paediatric Intensive Care. This also involves supporting children and families with any difficulties after hospital admissions, such as continuing to have thoughts or upsetting dreams about being in hospital.

Supporting parents to bond with a new born baby in hospital.

Helping children and families adjust to living with a heart condition and managing the demands of the illness and its treatment more generally.

Supporting siblings who have a brother or sister with a heart condition. Siblings can have a range of reactions and feelings and it can take time for them to make sense of what is happening. We are available to support sib-

lings directly and to support them through talking with their parents.

Supporting children and families who may have other difficulties such as existing worry and anxiety, low mood, behavioural problems, or learning disabilities who also have a heart problem. This can make living with a heart condition, coming to hospital, or having surgery more stressful and difficult to manage.

Supporting adolescents as they transition to adult cardiac services.

We really value your opinion and thoughts about the psychology service, if you have any comments, suggestions or ideas on how we might continue to improve the service we would love to hear them. You can either write to us at the hospital, telephone us (0117 342 8168), or email us at:

nell.ellison@UHBristol.nhs.uk

or
Vanessa.garratt@UHBristol.nhs.uk

From all the cardiac team here at Bristol Children's Hospital we wish you a very....

Merry Christmas



Peaceful New Year



Introducing the Cardiac Research Team!



We thought we'd introduce ourselves and tell you a bit about what we do. We are a growing band of experienced nurses delivering cardiac research within the Children's Hospital. There are currently 3 of us but we are hoping to make that 4 by the end of the year! There is currently one full time nurse, Karen Sheehan, and two part time nurses Kathy Selway and Carrie Cherrington. We work as part of the Bristol University Clinical Trials and Evaluation Unit (CTEU) to develop and deliver clinical research studies. We are based in the children's hospital and can often be seen on ward 32, PICU, outpatients and theatres. Our office is in the King David Building and we can be contacted on extension 28889 or bleep 6339.

We screen patients to see if they are eligible to take part in our studies. For those who are eligible we discuss the studies with the children and families and, if they are interested, take informed consent.

We work with families over the length of the study - whether that's simply for the duration of their inpatient stay or up to 5 years for some of our drugs trials. We book appointments and tests, make follow up calls, take samples, collect data or whatever each particular study requires. We are a point of contact for families and provide ongoing support and information throughout their time on a study. We also act as clinical experts helping to design future studies. We identify practical issues around delivering the studies, logistical problems and ways to overcome them, as well as educating the clinical teams involved in new studies.

Some of our current studies include:

AIMS - a 5 year long drug study looking at whether a drug called Irbesartan can stop the Aorta getting too big in patients with Marfan syndrome.

RVENCH - a surgical study looking at trying to better understand treatment options for patients whose heart condition has caused high

pressure in their lungs.

We have several studies nearly ready to publish including DECISION, which is looking at the use of blood and blood products during cardiac surgery and are helping to set up several new studies including a drug study for patients with BARTH syndrome, and a surgical study using a different way of replacing pulmonary valves which means the patient does not have to go on the heart lung machine. All the studies have one common feature – finding better ways of looking after our patients.

Our aim is to give all eligible patients the opportunity to take part in research, and to make the research experience a positive one for everyone. Whether you are a member of staff who wants to know more about what research is being conducted within your area; a patient or parent interested in taking part in current research; or a student wanting to find out about what research nurses actually do, we're happy to answer your questions.

Bronchiolitis: What you need to know



With winter upon us, it's that time of year when Bronchiolitis starts to rear its ugly head. Bronchiolitis is a common lower respiratory tract infection that affects babies and young children. Most cases are mild and clear up without the need for treatment within two-three weeks, other children have severe symptoms which may require hospital treatment.

Cardiac babies are at risk of catching bronchiolitis, just like any other baby, and those with a cyanotic heart defect (blue babies) are at a slightly higher risk of being more unwell.

Early signs and symptoms of Bronchiolitis are similar to that of a common cold; runny noses and coughing being the most obvious. Further symptoms such as high temperature, difficulty feeding and rapid or noisy breathing will often follow.

At this time of year Bronchiolitis is frequently caused by a virus known as **Respiratory Syncytial Virus (RSV)** which is spread through tiny droplets of liquid from coughs or sneezes of someone who is infected. There are other viruses that can cause similar symptoms such as Adenovirus, Rhinovirus, Parafu and Human Metapneumovirus.

However, despite knowing this there are no medications that can kill the viruses that cause bronchiolitis and the infection will usually resolve without the need for treatment within two weeks.

What to do if you suspect your child has Bronchiolitis

It is very difficult to prevent bronchiolitis but there are steps you can take to reduce the risk/ease symptoms:

- Discourage visitors into the home who are known to be unwell with cold/flu-like symptoms
- Ensure your child gets enough fluid to avoid dehydration
- Give simple over-the-counter medications to ease temperatures and discomfort such as Paracetamol or Ibuprofen (cardiac babies should check if they can take ibuprofen)
- Maintain thorough hand hygiene in the home (including siblings, visitors etc.)
- Wash or wipe toys and surfaces regularly with hot soapy water
- Keep infected children at home until their symptoms have improved



When to seek medical help?

- If you are in any way concerned for the wellbeing of your child
- If their breathing becomes laboured or they make unusual breathing sounds such as wheezing or grunting
- If they have taken less than half the amount of oral fluid that you anticipate for their last 2/3 feeds, or have not had a wet nappy for 8+ hours
- If their temperature is persistently high despite simple over-the-counter medications such as Paracetamol or Ibuprofen

Finally - If your child is scheduled to come into the hospital for any reason, but especially if this involves a procedure or surgery, it is very important that the team is notified. Please use the contact the Cardiac Nurse Specialist's (0117) 342 8286 who are also available for further advice/support if your child is unwell.

Faculty of Children's Nurse Education



Hello, my name is Sandra Batcheler and I am one of the Nurse Educators on the Faculty of Children's Nurse Education (FCNE) team. The FCNE team was formed just over a year ago with the aim of providing high quality education to children's nurses to support them in providing a high standard of treatment and care to children and their families.

My background covers a range of both adult and children's cardiac nursing in Birmingham, Leicester, Bristol and Cyprus. I have enjoyed educational roles in each of the establishments I have worked in and learnt a lot about the delivery of nursing care and nurse education in a variety of environments.

Since joining the FCNE team I have received a lot of support from the nursing and medical staff within the children's cardiac ser-

vices department to design and deliver two different University accredited courses. So far only nurses from Bristol Children's Hospital have attended the courses, but as from this autumn we will be welcoming nurses from other centres.

The Introduction to Children's Cardiac Nursing course is aimed at nurses with minimal experience of caring for children with cardiac anomalies who have an interest in developing their understanding of the principles of cardiac care and enhancing safe and effective ward and high dependency practice.

The Children's Cardiac Nursing: Care and Management course is aimed at nurses with a minimum of two years experience of caring for children with cardiac abnormalities. This course develops a more in-depth understanding of cardiac pathophysiology and its application to and influence on nursing care.

The student feedback has been extremely positive, with nurses stating that the courses have improved their knowledge and confidence when faced with caring for children with cardiac abnormalities. I'm sure the courses will continue to evolve with the continued input and support from the multi-disciplinary team.

Bristol cardiac review update

The Independent Review has now completed gathering evidence from patients and their families and is now starting meetings with a range of our staff, together with seeking the views of colleagues at other hospitals across the South West and South Wales networks. The Trust has already been assisting the Review in several ways, with

over 30 of our staff presenting on aspects of clinical governance and quality at three half day information sessions, together with submitting over 2,500 documents to the Review Evidence Team so far, to support the work of the Chair and Expert Panel. This evidence gathering phase is expected to be complete by Christmas and then the Review

expects that their report will be completed by Spring 2016.

We continue to look forward to the Review team helping us better understand how we have lost the trust of a small number of families, how we learn from this and what we need to put right.





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University Hospitals Bristol 
NHS Foundation Trust

Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.



Some useful numbers:

Ward 32: 0117 342 8332

Cardiac Nurse Specialists: 0117 342 8286/8578....or

email: cardiacnurses@uhbristol.nhs.uk

Cardiac Psychologists: 0117 342 8168

Welsh Cardiac Nurse Specialists: 02920 744753

Surgical Co-ordinator: 0117 342 8862

Outpatient queries: 0117 342 8860

Secretary to Dr's Martin & Hayes & Taliotis: 0117 342 8855

Secretary to Dr's Stuart & Walsh: 0117 342 8852

Secretary to Dr's Tometzki & Caldas: 0117 342 8853

Sec to Prof. Tulloh & Dr. Tsai-Goodman: 0117 3428856

Cardiac Physiology Dept (ECG/Echo): 0117 342 8181

Fetal Medicine Secretary: 0117 342 5394

LIAISE Service (previously PALS): 0117 342 8065

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/the-paediatric-cardiac-service/>

Events near you!

Transition Evening @ the Bristol Heart Institute

Tuesday 15th March 2016 - 6:30pm

The team warmly welcome you to meet the Adult Congenital Cardiac Team and see the facilities that the BHI offer as part of your transition to adult services (ages 15+, parents/ carers welcome). For further information please contact:

Jessica Hughes, Paediatric Cardiac Nurse Specialist - (0117) 342 8286

or email: jessica.hughes@uhbristol.nhs.uk



By invitation only...

Cardiac Christmas Party



@ The Royal Marriot Hotel

Sunday 13th December 2016: 2-4pm

Following the success of last year, and with the generous support of **The Grand Appeal** children who have undergone cardiac surgery between Oct 2014-Oct2015 will be receiving an invitation to the Cardiac Christmas Party! For further information please contact:

Lisa Patten, Paediatric CNS - (0117) 342 8286 or lisa.patten@uhbristol.nhs.uk