Information Leaflet for parents/carers

Patent Ductus Arteriosus (PDA) in Premature Babies
We have written this leaflet to help you understand more about Patent Ductus Arteriosus in premature babies and what will happen when your baby comes to Birmingham Children’s Hospital for their operation.

**What is Patent Ductus Arteriosus (PDA)?**

In the normal heart, the circulation of blood around the lungs is separate from the circulation around the rest of the body. However, before we are born there is a natural blood vessel that connects the lungs with the main circulation – the ‘ductus arteriosus’ (arterial duct). This allows the blood to bypass the lungs and helps the circulation to develop while we are growing in the womb.

After we are born this blood vessel usually closes during the first days of life, separating the lungs from the main circulation. Sometimes this blood vessel, the ductus arteriosus, fails to close by itself and remains open. This is known as Patent Ductus Arteriosus. It is also sometimes called Persistent Ductus Arteriosus. The PDA causes extra blood to flow into the lungs. The result is a kind of short circuit that leads to the lungs becoming congested with a build-up of blood.

**How common is PDA and who does it affect?**

PDA is most common in premature babies.

**What are the symptoms of PDA?**

A small PDA may have no symptoms, but a large PDA can cause breathlessness and may even require a ventilator to support the baby’s breathing.
How is PDA diagnosed?

A heart scan (Echocardiogram) can diagnose a PDA and can be used to help decide if an operation is needed.

What is the treatment for PDA in premature babies?

If the duct hasn’t closed after a few days then we usually try medicines to try to get it to close. If these medicines do not work or if your baby is too sick to have these medicines then it may become necessary to perform an operation to actually tie-off the duct.

We always try to avoid an operation if possible but if the duct remains open despite medical treatment then an operation to close the duct may be the only way of preventing this congestion of blood in the lungs.

The Operation

The surgery will be carried out by specialist heart surgeons at Birmingham Children’s Hospital who treat all the different types of heart conditions that can happen in babies. The operation is performed through an incision (cut) in the left side of the chest, beneath the shoulder blade; the incision is about 2½cm (one inch) long and the stitches are invisible ones underneath the skin that will dissolve.

Through this incision the lung is gently pushed out of the way and the surgeon is able to get to the main blood vessels and the duct that connects them together.
The duct is then tied off with a ligature and/or with a tiny metal clip as shown in the pictures below.

**What are the risks and benefits of the operation?**

All surgery, however minor has risks. These risks can come from

- Having a general anaesthetic
- The actual surgery

The Anaesthetist will explain to you about your baby’s general anaesthetic in more detail.

The surgery itself is a straightforward procedure that is commonly performed by heart surgeons. The risk of the surgery itself is very low and the risk of any major bleeding or of your baby not surviving the surgery is less than 1% (1 in 100).

However, it is important for you to understand that this is a major operation involving the major blood vessels inside the chest; premature babies are very fragile and the surgery is very delicate.
Your baby still has a long journey ahead in terms of all the health risks and challenges of being premature but closing the PDA will help towards success in this journey. Our statistics tell us that 95% of premature babies who need to undergo this operation will be alive at 30 days after surgery.

Sometimes the lung may not fully expand after the surgery in which case a drain may be needed to allow the lung to reinflate fully and to drain away any fluid. Less than 5% (1 in 20) babies would ever need such a drain.

The scar generally heals very well in premature babies and we do everything we can to keep it as small as possible. We usually place butterfly stitches (‘steristrips’) across the wound to help it heal and these stay on for 7 days.

- Large ducts that require a baby to need the support of a ventilator are life-threatening if they are not closed. This is because the short circuit of blood through the lungs causes heart failure and low blood pressure that can impair the blood supply to the other major organs, especially the bowel. The congested lungs are always at risk of infection, particularly when dependent on the ventilator.

- Moderate sized ducts that do not close on their own can also be a risk. Even if a baby does not need the support of a ventilator the effect of a moderate sized duct is that the lungs remain congested with blood generating high blood-pressures in the lungs. These high blood pressures will ultimately damage the lungs if the duct is not closed.
The risks of surgery have to balance against the benefits for your baby. There can be enormous benefits from this relatively simple operation.

It is important to remember that we would never suggest surgery unless we were concerned.

**Your Journey to Birmingham Children’s Hospital (BCH)**

The operation will be performed at BCH, which is where the regional children’s heart surgery unit is based. The operation will be performed by one of the consultant heart surgeons and you will have a chance to meet them and discuss the operation when you arrive.

Your baby will be transferred by ambulance in an incubator together with a doctor and nurse from your local Neonatal Unit. You cannot usually travel in the ambulance with them so if you want to come to the hospital with your baby then you will need to arrange to travel separately. Ideally we would always prefer for you to be able to come as well so that you have a chance to meet us and to discuss the surgery. Your baby will have their surgery and will then be transferred back to your local Neonatal Unit on the same day.

**How to Find Us**

For more information about getting here please go the BCH website at: [www.bch.nhs.uk](http://www.bch.nhs.uk) and click on “How to Find Us” for maps and directions to the hospital.
What happens next?

On arrival at BCH, you will be directed to the recovery area in main theatres, which is on the second floor of the main hospital building. It is well signposted and there is an entry buzzer outside the double doors where a member of staff will let you in. If you are not sure where you need to go, please ask. Staff will be happy to help. Here, your baby will be reassessed and everything checked over. We usually perform a quick heart scan (Echocardiogram) to confirm the size and position of the duct.

The Anaesthetist, Cardiologist and Surgeon will all check they are happy with everything and will introduce themselves to you and answer any questions you may have. Your baby will then be taken into the operating theatre for their operation. Although the surgery itself takes about 30 minutes it is usually about an hour to an hour and a half in total before returning to the recovery area. This is because it takes time to transfer your baby from the incubator to the operating table. Often a new drip and or breathing tube is also needed before starting the operation.

You can choose wait in the recovery area or you can go to the canteen or even outside for some fresh air while the operation is going on. Once your baby returns to the recovery area then the doctor and nurse will check that everything is stable and then make plans to return to your baby to your local Neonatal Unit.
Taking Consent

Before your baby has their operation you are required to give your consent for the surgery to be carried out. It is important that you fully understand what is wrong with your baby and about the risks and benefits of the planned surgery before you sign the consent form. This will be explained to you in detail by the doctor but please ask if there is anything you are not sure about. The doctor will be happy to answer any further questions you may have.

Ideally it will be the surgeon performing the operation who takes consent, in which case they will do this when you meet them at BCH.

If you are not able to come with your baby, your consent for surgery will be taken either by the Cardiologist when he talks to you at your local Neonatal Unit or by the cardiac surgeon himself by telephone. This will need to be arranged beforehand.

Interpreting Services

There is an interpreting service available at BCH. If you need an interpreter please ask your local Neonatal Unit to contact the Interpreting Department directly on 0121 333 8015 before your transfer to BCH for this to be arranged.

Who can I contact if I am concerned or have any further questions?

If you have any more questions or need any further information please contact the Cardiac Nurse Specialists on 0121 333 9449.
Frequently Asked Questions

Why can’t the operation be done here at our local Neonatal Unit?

This is highly specialised surgery that is best performed by a team of specialists, not only the surgeons and anaesthetists but also the theatre nurses and theatre equipment. These facilities are only available at BCH and we believe that your baby has the best chance if the operation is done where all the back-up and support services for heart surgery is available. The whole team at BCH are experienced at performing these sorts of operation every day.

I have heard that a duct can be closed with a special device without needing an operation, why can’t my baby have that?

It is true that there are now tiny expandable devices that can be used to plug off ducts that can be delivered through a long wire passed up from a blood vessel in the groin. However, this can only be done in much older children since the blood vessels in a premature baby are much too small for one of these wires to fit.

Not only does your baby have a large duct, but also he/she cannot wait until they are heavier than 3kg as his/her life could be at risk if left with this duct.
Looking after and sharing information about your child

Information is collected about your child relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some of your information with other people and organisations who are either responsible or directly involved in your child’s care. This may involve taking your child’s information off site. We may also have to share some of your information for other purposes; such as research etc. Any information that is shared in this way will not identify your child unless we have your consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403/8541.

National Congenital Heart Disease Audit - NCHDA
National Institute of Cardiovascular Outcomes and research – NICOR

NCHDA is a national database used to hold patient information. The information is used to make sure that all cardiac surgery is carried out the same high standards throughout the United Kingdom.

What information is held on the database?

The database holds information about all heart operations.

Information held will include:
• The patients name
• The patients age
• The patients post code
• The patients condition
• The operation carried out and its outcome
How is the information used?

This information is a legal requirement used by the government to monitor how well hospitals are performing. The information is externally checked and validated. Each year, several sets of patient notes are checked by independent auditors against the information on the database to make sure that the information is correct.

Why is this information important?

This information is important to make sure that all cardiac centres across the country are maintaining the same high standards of care.

Parent/Carers Support

British Heart Foundation
Heart Helpline: 0300 330 3311
Web: www.bhf.org.uk

Children’s Heart Federation
Free Infoline: 0808 808 5000
Web: www.chfed.org.uk

This leaflet has been produced by the Consultant Paediatric Cardiologist and Consultant Paediatric Cardiac Surgeon on behalf of the Cardiac Unit.
Further Information

We hope this information leaflet will help you to understand about your child’s condition. This leaflet was produced using the latest evidence available and is based upon current practice. Further details are available upon request. Before you sign the consent form, it is important that you talk to your child’s doctor and ask any questions you may have.

If you feel you need any more advice or have any concerns you can also contact the Cardiac Nurse Specialists on 0121 333 9949.

Health information and Internet access is also available in the Family Health Information Centre at the hospital.

Tel: 0121 333 8505
Email: child.infoctr@bch.nhs.uk