

Fetal - Perinatal Cardiology Service

## **The Fetal Cardiology Team**

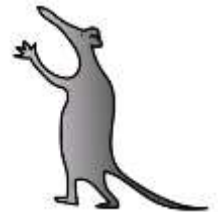
Information for parents

### **Introduction**

The Fetal Cardiology Team are a team of experienced doctors and nurses who specialise in the care of babies with heart conditions, both before and after they are born. We are based at Alder Hey Children's NHS Foundation Trust Hospital (AH) in Liverpool and hold twice weekly antenatal clinics at the nearby Liverpool Women's Hospital (LWH).

### **The Fetal Team**

Dr Joyce Lim	- Consultant Paediatric Cardiologist / Fetal Cardiologist
Dr Ram Ramaraj	- Consultant Paediatric Cardiologist / Fetal Cardiologist
Dr Umer Agarwal	- Consultant in Obstetrics, Maternal and Fetal Medicine with a specialist interest in Fetal Echo (based at LWH)
Marie Murphy & Gill McBurney	- Fetal Cardiac Nurse Specialist / Paediatric Cardiac Nurse Specialists
Sharon Clarke and Ann Rhodes	- Specialist Cardiac Sonographers
Fetal Medicine Midwives	- Based at LWH



### **Your Antenatal Cardiac Appointment at Liverpool Women's Hospital**

We see women at Liverpool Women's Hospital fetal echo clinic for two reasons:

- You would now have had your routine anomaly scan at your local hospital, and they have raised concerns about your baby.
- You have been offered an appointment here because of a risk factor in your medical, family or obstetric history, that increases your risk of having baby with congenital heart disease.

An echocardiogram (echo) is a scan of your baby's heart while your baby is still in the womb. It is similar to the routine scans you have while you are pregnant, although in this scan we focus on your baby's heart. We use ultrasound to see how the heart is developing and to look at how the blood flows. In many cases this confirms that the heart has developed normally. Some heart problems can be detected antenatally, but there are a small number of conditions that can only be detected after birth.

During your antenatal cardiac clinic appointment at the Liverpool Women's Hospital your baby will have a fetal heart echo and a review by a Consultant Paediatric Cardiologist who specialises in fetal hearts. This is usually jointly done with the Fetal Medicine Consultant who will provide input on other aspects of your baby's development and Obstetric care. Your consultation will be supported by a Fetal Cardiac Nurse Specialist and Fetal Medicine Midwife.

Once we have completed the scan, we will talk with you about the results. Should we find anything on the echo which indicates a problem, we will explain what it means for baby and provide you with any relevant literature / diagrams, and a letter detailing our findings.

We will provide support, information and advice on all treatment options available to you and whether your baby is likely to need medical and/or surgical treatment.

Depending on the cardiac findings you may be asked to come back for one or more scans before your baby is born. One baby out of every ten who is found to have a heart condition may have problems with the structure of other organs. This may also have been identified during your pregnancy. In such cases, where baby's heart and other organs are affected, you will be counselled jointly by Fetal Cardiology and Fetal Medicine / Obstetric teams. They will talk to you about possibility of underlying chromosomal / genetic conditions that happen in a small number of cases of congenital heart disease.

Should you wish, you can be offered an amniocentesis procedure to look for baby's genetic makeup or blueprint. This may help you make further decisions regarding your pregnancy.

We may also ask one of our neonatal team members to see you during your pregnancy to talk to you about how they would support you and your baby after birth, and what possible care your baby may receive. You could also choose to visit the neonatal unit at Liverpool Women's Hospital at one of your appointments, should you wish to do so.

Between your appointments, we will ask your local hospital to continue providing your routine antenatal care. You must continue seeing your own midwife and keep appointments of other antenatal clinics that you may attend. If we feel that your care for delivery should be transferred to Liverpool Women's Hospital, we will facilitate this for you and inform your fetal medicine liaison midwife, by way of our report.

We will also make plans with you and your family jointly regarding timing, place and mode of giving birth. In most cases, it is safe for you to undergo a vaginal birth like most women would do routinely. But where your baby's heart condition or any other factor in your history suggests that you may need a caesarean section, we will discuss this with you

### **Antenatal Cardiac Clinic at Alder Hey and further support / advice from the Fetal Cardiac Nurse Specialists**



In addition to your appointment at Liverpool Women's Hospital, the Fetal Cardiac Nurse Specialists (FCNS) can arrange for you to attend an antenatal clinic at Alder Hey. At this clinic they can provide you with further information of what is likely to be involved during your baby's hospital stay, and the practicalities of being in hospital. If your baby does require treatment immediately after birth, they can advise you on Alder Hey's parents' accommodation to enable you to stay with your baby when you are discharged from the maternity centre. They can also arrange a virtual visit to the cardiac ward and critical care unit where your baby will be staying.

If you wish, they can arrange for you to meet one of our heart surgeons, or another Consultant Paediatric Cardiologist. The Fetal Cardiac Nurse Specialists (FCNS) can arrange for siblings to meet the play therapists who can help them to understand what will happen when their brother or sister is born, and why you may have to spend time in hospital with your baby. If you feel it beneficial, they can arrange for you to meet with other parents who have had similar experiences. There are many families who are willing to share their experiences and offer you peer support.

The Fetal Cardiac Nurse Specialists are there to support you throughout your pregnancy. It can be a worrying time for you, and they want to ensure that you have as much information and support as you need, both before your baby is born and afterwards. They are always happy to answer any questions, and they are your link with your Cardiologist. They can liaise about any queries you may have in between your appointments.

If you need to contact the Fetal Cardiac Nurse Specialists you can telephone - **0151 252 5642** and leave a message with your contact details, the line is checked Monday - Friday (excluding bank holidays) at midday, one of the team will get back to you as soon as they can. Alternatively, you can call the Paediatric Cardiac Nurse Specialist Team Monday - Friday 8.30am - 4.30pm, excluding weekends and bank holidays on telephone - **0151 252 5291**, they are based at Alder Hey. Please leave a message, including your name and contact telephone number and they will call you back as soon as possible. The voicemail service is private and confidential, and it is listened to by the Cardiac Nurse Specialist Team.

### When your baby is born

Not all babies require treatment immediately after birth. Some babies can be assessed at their local special care baby unit and discharged home with no, or some support, and a cardiac outpatient follow-up appointment.

If your baby needs come to Alder Hey after birth, transfer will be coordinated by the transferring hospital once your baby is stable.

- Some babies may need to come to Alder Hey for treatment and a long stay.
- Some babies come to Alder Hey for an assessment and may stay or go home with cardiac outpatient follow-up and may require home support by community nurses.
- Some may need a one-off cardiac review some days / weeks / months following birth, and some babies may have regular cardiac outpatient appointments throughout their life.
- There are times when your baby may not require an immediate echo scan following birth. This may need to be done in the days / weeks / months that follow, and the Cardiologist will advise time frames / plan for this.

### The Paediatric Cardiac Nurse Specialist Team at Alder Hey

The two Fetal Cardiac Nurse Specialists (Marie and Gill) are also part of the wider Paediatric Cardiac Nurse Specialist Team (PCNS) based at Alder Hey. The PCNS team is a designated team of ten senior Paediatric Cardiac Nurses. The team has a vast amount of experience in Paediatric Cardiology, having nursed an abundance of children with cardiac problems from birth through to young people / older teens.

The common goal of the PCNS team is to provide ongoing emotional support, information and practical advice for children and teenagers with a heart condition, and their families. The PCNS service carries on to teenage years (Transition service) and eventual transfer to adult services. We have a dedicated Cardiac Transition Nurse Specialist based within the PCNS Team.



Emotional support to heart families is paramount. At Alder Hey we have a Psychology Team, Claire House Hospice Representatives and a Palliative Team who can provide support /

counselling whenever it is needed. The PCNS Team can refer, appropriately, into any of these services, as required on an individual basis. The PCNS team also has extensive links with many cardiac charitable organisations that can assist heart families throughout their journey, in providing them with peer support.

## Useful Contacts

Before birth – if you have any questions or concerns you can speak to the Fetal Cardiac Nurse Specialists – Marie Murphy & Gill McBurney, based at Alder Hey Children’s NHS Foundation Trust

After birth – You can speak with the Paediatric Cardiac Nurse Specialist Team – a team of ten senior Cardiac Nurses, based at Alder Hey Children’s NHS Foundation Trust.

Contact numbers included in this leaflet.

## Websites

Antenatal Results and Choices, [www.arc-uk.org](http://www.arc-uk.org) - provides information about making choices in pregnancy

Arrhythmia Alliance (for rhythm patients), [www.hearhythmalliance.org.uk](http://www.hearhythmalliance.org.uk), 01789 867501

British Heart Foundation, [www.bhf.org.uk](http://www.bhf.org.uk), 0300 330 3311

Children’s Heart Association (local to the NW), [www.heartchild.info](http://www.heartchild.info), 01706 221988

Children’s Heart Federation, [www.chfed.org.uk](http://www.chfed.org.uk), 0300 5610065

Children’s Hospital of Philadelphia, [www.chop.edu](http://www.chop.edu)

Contact (for condition and welfare information), [www.contact.org.uk](http://www.contact.org.uk), 0808 808 3555

Downs Heart Group, [www.dhg.org.uk](http://www.dhg.org.uk), 0300 102 1644

Little Hearts Matter (for single ventricle anatomy patients), [www.lhm.org.uk](http://www.lhm.org.uk), 0121 455 8982

Max Appeal (for Di George/22q11 families), [www.maxappeal.org.uk](http://www.maxappeal.org.uk), 0300 9992211

Somerville Foundation (for young people), [www.thesf.org.uk](http://www.thesf.org.uk), 01473 252007

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child’s treatment.

This information can be made available in other languages and formats if requested.

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