



## **Cystic Fibrosis (CF) Baby Clinic**

### **Where is it?**

The CF baby clinic is held in the Respiratory and Cystic Fibrosis Unit on the ground floor of Birmingham Children's Hospital.

### **When is it and how is it organised?**

The CF baby clinic is held every month on a Tuesday afternoon or Wednesday morning. On arrival in the department you will be allocated to a clinic room for the duration of your appointment to minimise any risk of your baby being exposed to infection.

### **Who will you meet?**

You will meet the CF team at clinic. The team includes specialist CF doctors, nurses, dietitians, physiotherapists, pharmacist, family support worker and psychologists.

### **Why are weight, length and oxygen saturations measured?**

These are measured to monitor all aspects of your baby's health and to ensure he/she are growing and developing well. Your baby's saturations are a measure of the oxygen levels in their blood. Please bring your red book to help communication with your community team.

### **When and why will bloods and X-rays be taken?**

Blood tests and X-rays are taken soon after diagnosis with CF and then routinely annually thereafter. Sometimes extra blood tests and X-rays are needed.

The blood tests are used to check all aspects of your baby's health and to confirm the genetic alterations which your baby has. A chest X-ray gives a baseline from which to monitor your baby's progress.

### **What is a cough swab and why is it done?**

A cough swab is taken to identify "germs"/ bacteria in your baby's airways.

"Germs" can cause an increase in cough, loss of appetite and weight loss. Some children may not have any symptoms. Although not all "germs" cause problems, it is still important to treat germs which can cause problems when they have been found.



## Simple measures that may reduce the risk of exposure to infection.

It is impossible to **completely** prevent children from coming into contact with infections and "germs" but these are some suggestions that might help reduce the risk:

- First and most important good hand washing with liquid soap and careful drying
- Avoid people with viral infection i.e. coughs and colds
- Change cut flower water daily
- Wash hands after handling pets and animals
- Avoid bath toys that can hold water. Toys need to be easily washed and dried
- Keep sink areas, washing machines and dishwashers clean and dry

## Immunisations and Infectious diseases?

It is important that babies with CF are kept up to date with all their routine immunisations. Your health visitor will be able to advise you on this.

If your baby has contact with chicken pox you will need to contact the CF team for advice as your baby may need a treatment medication.

Children with CF should have the flu vaccine annually. They can have it if they are older than 6 months during the flu season. You need to make an appointment with your baby's GP practice to have a flu vaccine.

## The CF Registry

The UK CF registry monitors the health of people with cystic fibrosis throughout the UK. The main objective is to help, maintain and improve standards of care. You will be asked to give consent for your baby to take part in the CF Registry.

You will be given further information and details about the registry by your CF team.

**If you have any questions or concerns about this information please contact our CF Nurse Specialists:  
Telephone: 0121 333 9248**