

## Contacting the team

If you have any concerns or wish to contact the CF team, please contact the paediatric respiratory nursing team on 0151 430 1938 / 07584 143 785 who are available Monday to Friday 8am-5pm.

Your Child's CF Team contact details are:

Consultant Paediatrician: via Medical Secretary on 0151 430 1453 option 5.

Paediatric Respiratory Nurse Specialists: 0151 430 1938 or Mobile 07584 143 785.

Respiratory Sister: 0151 430 1453 or Mobile 07584 143 785.

Paediatric Dietician: 0151 430 1201.

Paediatric Physiotherapist: 0151 430 1157.

Paediatric Respiratory Admin Co-ordinator: 0151 290 4044.

Whiston Hospital  
Warrington Road,  
Prescot, Merseyside, L35 5DR  
Telephone: 0151 426 1600

St Helens Hospital  
Marshall Cross Road,  
St Helens, Merseyside, WA9 3DA  
Telephone: 01744 26633

# Information for families of newly diagnosed cystic fibrosis patients

If you need this leaflet in a different language or accessible format please speak to a member of staff who can arrange it for you.

اگر به این بروشور به زبان دیگر یا در قالب دسترس پذیر نیاز دارید، لطفاً با یکی از کارکنان صحبت کنید تا آن را برای شما تهیه کند.

Jeśli niniejsza ulotka ma być dostępna w innym języku lub formie, proszę skontaktować się z członkiem personelu, który ją dla Państwa przygotowuje.

Dacă aveți nevoie de această broșură într-o altă limbă sau într-un format accesibil, vă rog să discutați cu un membru al personalului să se ocupe de acest lucru pentru dumneavoastră

如果您需要本传单的其他语言版本或无障碍格式，请联系工作人员为您安排。

إذا احتجت إلى هذه النشرة بلغة أخرى، أو بتنسيق يسهل الوصول إليه، يرجى التحدث إلى أحد الموظفين لترتيب ذلك لك.

This leaflet is to provide you with some information on the service we provide and a list of contact details for the Cystic Fibrosis Team.

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

This is held every Monday afternoon in Paediatric Outpatients, Level 2, Whiston Hospital.

In order to reduce the risk of cross-infection, we run a segregated clinic, which means that each patient is given a specific time slot and allocated their own room for the duration of the appointment. At each clinic, your child will have their height and weight taken and be seen by one of our two paediatric consultants, a paediatric respiratory nurse, a dietitian and a physiotherapist.

### **Annual review/ interim review**

Once per year, all children will have an annual review appointment whereby you will be seen by your Whiston team and Alder Hey team together.

Prior to this appointment you will be required to have the following investigations completed for your child, such as an ultrasound scan, chest x-ray and blood tests etc.

The annual review process will be explained in detail by the paediatric respiratory nurses. The two teams work closely to ensure your child has the best possible care over the coming years.

Approximately 6 months after annual review, an interim review will be completed. You may not have to physically attend and you will receive a letter from the team to say we have discussed your child at a meeting and any changes to their plan will be explained.

### **Inpatient care**

If your child needs to come into hospital for blood tests these will be carried out by the paediatric day unit.

If you have any concerns regarding your child, you have open access to the hospital via 0151 430 1627. You can contact this number for advice any time day or night.

**In an emergency you must always call 999.**

Inpatient admissions will be on the paediatric unit and your child will be nursed in a cubicle throughout their stay.

We do allow one parent/carer to stay overnight with their child whilst they are an inpatient.

We will work with you to organise any planned admissions for intravenous antibiotics to lessen the interruption to your normal routine.

Where possible, we will try to utilise Hospital@Home enabling your child to have the antibiotics administered in your own home.