



# The Cystic Fibrosis Service at GOSH

Information for families  
of newly diagnosed children

Great Ormond Street Hospital  
for Children NHS Foundation Trust



**Great Ormond Street Hospital (GOSH) provides a specialist cystic fibrosis (CF) service to approximately 180 children.**

**This leaflet will give you some information on the service we provide and contact details for the CF Team. Please contact us if you have any queries or concerns regarding your child's health.**

**Further information is also available on the GOSH website at [www.gosh.nhs.uk/medical-conditions/clinical-specialties/cystic-fibrosis-information-for-parents-and-visitors](http://www.gosh.nhs.uk/medical-conditions/clinical-specialties/cystic-fibrosis-information-for-parents-and-visitors).**

## CF Clinic

Children with CF usually attend hospital for an outpatient check up on a two to three monthly basis depending on individual health needs. Your child will be seen by the CF team in our outpatient clinic on the 1st floor of the Royal London Hospital for Integrated Medicine (RLHIM – also on Great Ormond Street). Clinics take place every Tuesday afternoon.

We are very mindful of the risks of cross infection in CF and in order to minimise these risks we run a segregated clinic, which means that each family is given a specific time slot and allocated a single room for the duration of the appointment. When you arrive in clinic you will be shown to your allocated room. In order to make this system work, we have specific appointment times. It is extremely important that you attend on time, otherwise your appointment may be considerably delayed and you may not get to see all members of the team. Of course, inevitably

there are times when the clinic is very busy or circumstances lead to a hold up in the timings. If a room is not immediately available, you may be asked to wait in a waiting area, away from other children with CF, until a room can be made available.

Our clinic assistants will measure your baby's weight and length (height). Following this, various members of the CF team will come to see you in your allocated room. At every appointment you will see a doctor (often one of our Consultants), a Clinical Nurse Specialist and a Physiotherapist. The Dietitian, Psychologist, Social Worker and Family Support Worker are all available in clinic and will see you as often as necessary. Once your child is about four years old, they will also have a lung function test at each clinic visit (more details about these tests can be found on our website at [www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/lung-function-tests/](http://www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/lung-function-tests/)

## Annual Review

This is a very important part of your child's care and consists of a detailed review of all aspects of CF once every year. It gives each member of the CF team the opportunity to review all areas of your child's treatment thoroughly and to carry out some necessary yearly tests. These include:

- Chest x-ray
- Specialised lung function tests (pre-school upward)
- Exercise test (aged six years upward)
- Blood tests
- Other types of x-rays, scans, tests if they are needed

You should expect to be in the hospital for quite a large part of the day – usually between four and six hours. Not all the results of the various tests are available on the day, some may take several days. Approximately six weeks after the annual review, we will give you a follow up appointment for CF Clinic.

At this appointment, a Consultant will review all the results with you and discuss plans for future treatment. The CF team will have reviewed the results well before this appointment and if there are any problems or concerns which need attention, you will be contacted well before the six week follow up so that any appropriate treatment or further tests can be arranged.



## Inpatient Care

Most children with CF do not need to come in to hospital often. The most common reasons are for treatment of chest infections or for investigations of other problems. If your child does need to be admitted to GOSH, they will usually be admitted to Badger Ward (our respiratory ward). Sometimes an admission may take place at your local hospital. All the arrangements for the admission will be discussed with you when the decision is made and more detailed written admission information will be provided so that you know what to expect. At GOSH, we always provide facilities for one parent to stay with their child.

## Home Visits

The CF service provides an outreach service for children under our care. Usually our Clinical Nurse Specialist and Physiotherapist visit but other members of the team such as our social worker also make visits from time to time. These visits are made for specific reasons following discussions within the CF team and are not available on request other than in exceptional circumstances.

## Network Care

As a specialist centre for CF, the team at GOSH works closely with a limited number of local hospitals. This means that, depending on where you live, you may not need to travel to GOSH for all of your appointments. However, it is very important that some of the appointments are at GOSH so that the GOSH CF team can ensure that your son or daughter is receiving the specialist care they need. If your child is very well and their condition stable, a visit to GOSH once a year for a full annual review (see later) plus one or two other visits may be sufficient.



You can of course always request an appointment here, even if your planned appointment is not due for some time.

The GOSH team also hold clinics at the networks they share care with, generally where there are larger numbers of children with CF. Currently, these include:

- Basildon Hospital
- Luton & Dunstable Hospital
- Bedford Hospital
- Chelmsford Hospital

## The CF Team

### *Consultants:*

Dr Colin Wallis, Dr Ranjan Suri,  
Dr Paul Aurora

Dr Helen Spencer (Respiratory & Transplant Physician) & Professor Rosalyn Smyth (Dean of the Institute of Child Health) also participate in the consultant rota for CF clinic

### *CF Fellow:*

This changes on a yearly basis

### *Clinical Nurse Specialists:*

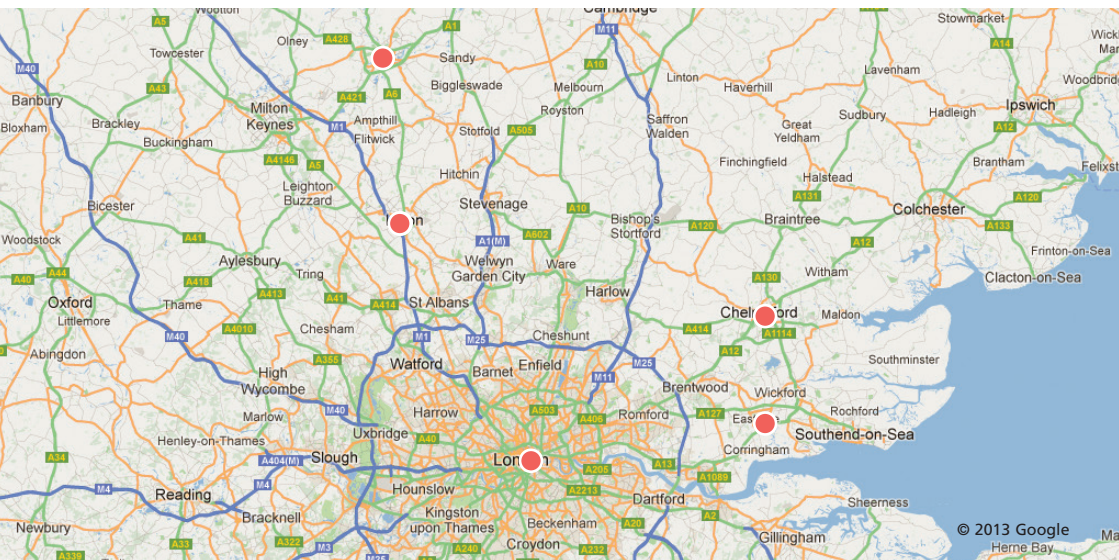
Denise Sheehan & Charlotte Dawson

### *Specialist Physiotherapists:*

Louisa Hill & Sarah Rand (outreach)

### *Specialist Dietitians:*

Elizabeth Owen & Marie Creedon



*Specialist Psychosocial team:*

Mandy Bryon & Petra Titlbachova

*Clinicians Assistant:*

Amy Watford

*CF Secretary:*

Carol Wragg

*CF Unit Manager:*

Ammani Prasad

All of the CF consultants take responsibility for the care of all the children in the CF clinic and you will meet them all over a period of time. When you come for your education day you will be informed of the named consultant who will take overall responsibility for your child's care. This does not mean that this is the person you will automatically see at clinics but it will be the person who over the course of your time at GOSH will, whenever needed, take the lead on any complex issues and deal with any concerns which may arise. There is also a lead consultant for CF, who is involved in the day to day management of the unit and currently this is Dr Suri.

## Contacting the team

If you have any concerns or wish to contact the CF team for any reason this can be done by telephone or e-mail, the contact details can be found below. For usual childhood illnesses (ear infections, sore throats and colds for instance) your first point of call should be your family doctor (GP), who can contact us directly if they have any concerns. If however you are concerned about anything at all that you feel might be CF-related or have a general query then please contact us either by telephone or, for non-urgent queries only, e-mail.

Telephone calls are answered by the CF secretary who will place your call on a data log and the appropriate team member will return your call, usually on the same day for clinical issues.

If the call is for a more urgent clinical issue, a member of the CF team (usually our Clinical Nurse Specialist or CF Fellow) will be contacted immediately to deal with the problem.

For urgent CF-related medical queries out of normal office hours, please ring Badger Ward where details of the problem will be taken. If appropriate the registrar on-call will be contacted and will return your call.

E-mail can be used for non-urgent issues but due to the inherent risks in this type of communication,

we will ask you to sign a consent form giving your permission for us to communicate with you electronically.

If you have any concerns regarding the service or would like to discuss a particular issue please contact the CF unit manager via the CF office number or e-mail.

## Cystic Fibrosis Unit Contact Details

GOSH switchboard	020 7405 9200
CF Office	020 7762 6714
Badger Ward	020 7829 8813
E-Mail	<a href="mailto:cysticfibrosisunit.query@gosh.nhs.uk">cysticfibrosisunit.query@gosh.nhs.uk</a>

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Compiled by the CF Team

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