

The Cystic Fibrosis Service at GOSH

Contact details

GOSH switchboard **020 7405 9200**

For individual extensions or bleep numbers, please dial the switchboard

CF team

CF office 020 7905 2328

Badger ward 020 7829 8813

Consultants

via secretaries on ext 5453

Dr Colin Wallis, Dr Paul Aurora,
Dr Ranjan Suri & Dr Helen Spencer

Clinical nurse specialists

Denise Sheehan 020 7905 2328 or bleep 0581

Charlotte Dawson (outreach) 07979 770292
or bleep 0154

CF coordinator/ Senior research physiotherapist

Ammani Prasad 020 7905 2328 or ext 1119

Senior physiotherapists

Louisa Hillbleep 0464

Sarah Rand (outreach) 07824 821412

Dietitians

Liz Owenbleep 0300

Marie Creedonbleep 0899

Psychologists

Mandy Bryonext 0501

Netalie Leviext 5561 or bleep 1023

Social worker

Petra Titlbachovableep 2094

Contacting the team

If you have any concerns or wish to contact the CF team for any other reason, the first place to telephone during office hours is the CF office direct line. If you have a specific problem, please call the appropriate team member directly. All our contact details are on the back page of this information sheet. If you have an urgent CF related problem outside of office hours, you should either contact your family doctor (GP), local consultant or the on-call respiratory registrar via GOSH switchboard.

Network team (if applicable)

Local hospital: _____

Local consultant: _____

CF link nurse: _____

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Compiled by the Cystic Fibrosis team in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street
London WC1N 3JH

www.goshfamilies.nhs.uk

www.childrenfirst.nhs.uk

Information for families of newly diagnosed children

Great Ormond Street Hospital for Children NHS Trust

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

CF clinic

This is held every Tuesday afternoon in our outpatient clinic on the 1st floor of the Royal London Homoeopathic Hospital (RLHH), which is a few hundred metres from GOSH.

In order to reduce the risk of cross-infection between patients, 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. When you arrive in clinic, you will be shown to your allocated room. The clinic assistants will come in to measure your child's height and weight, after which the members of the CF team will visit you and your child in the same room.

We have two appointment times: 1.30pm and 3pm. 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. At each appointment, you will see a doctor (often one of our consultants), a clinical nurse specialist and a physiotherapist. When your child is around four years old, he or she will have lung function tests at each clinic. The dietitian, psychologist and social worker will also see you as often as necessary.

This information sheet will give you some information on the service we provide and a list of contact details for the CF team. Please contact us if you have any queries or concerns regarding your child's health.

Network care

As a specialist centre for CF, the team at GOSH works closely with some local hospitals. This means that you may not need to travel to GOSH for all your appointments.

However, it is very important that you attend GOSH appointments in between your local appointments so that your child can receive the specialist care that he or she needs. If your child is well and his or her condition is stable, a visit to GOSH for an annual (once a year) review and one other outpatient clinic may be sufficient. You can, of course, request an appointment at other times, even if your planned appointment is not due for some time.

The GOSH CF team also hold clinics at some local hospitals – generally where there are larger numbers of children with CF. These include:

- Basildon Hospital
- Luton and Dunstable Hospital
- Bedford Hospital
- Chelmsford Hospital

The North Middlesex and Whittington Hospitals also have a joint respiratory clinic, which one of our consultants attends once or twice a year. Details of your network team are on the back of this information sheet.

The annual review

This is a very important part of your child's care. 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 annual tests. These include a chest x-ray, more specialised lung function tests, an exercise test, blood tests and occasionally other types of x-rays or ultrasound scans depending on your child's needs.

You should expect to be in the hospital for quite a large part of the day – usually between four and six hours. Approximately six weeks after the annual review appointment, we will give you a follow up appointment with a consultant when you will go through all the results together and discuss any plans for future treatment.

Inpatient care

If your child needs to come into hospital for investigations or treatment, they will either be admitted to GOSH (usually Badger Ward) or your local hospital, depending on the type of tests or treatment needed and whether these can be done locally. All the arrangements for the admission will be discussed with you if and when we decide that your child needs to come into hospital. If you do have an admission to GOSH, one parent is always invited to stay with their child.