



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Welcome to the Immunology Department

This information sheet gives you an outline of how the Immunology Department at Great Ormond Street Hospital (GOSH) looks after you and your child or children. It also provides contact details for various members of the team. It is a good idea to have the leaflet with you when you are away from home in case you need to contact us in an emergency.

The immunology team includes consultants, specialist nurses, junior doctors, psychologists, ward nurses and play specialists. Most of your child's outpatient care will be closely supervised by a consultant working in collaboration with specialist nurses, while the other members of the team will be involved in any day case or inpatient stays. Other specialists closely involved with the department include psychologists, social workers, dietitians and physiotherapists.

Outpatients

Most of your child's care is likely to take place on an outpatient basis (that is, they will not need to stay in hospital overnight). He or she will have one named consultant, and when you attend the outpatient clinic you will be seen by this doctor, or sometimes by a registrar working closely with them. One or more of the immunology specialist nurses may also be involved if your child attends GOSH regularly.

The care of your child will be shared with a paediatrician at your local hospital and your family doctor (GP). It is very important to maintain these contacts locally.

If your child is unwell, you should consult your GP or local team initially. In some cases, you may be given direct access to the children's ward in the local hospital. If your child needs urgent admission to hospital, this will normally be first to the local hospital before any admission to GOSH is considered.

However, if you need to discuss any aspects of your child's condition or their care, you can contact your consultant or immunology nurse specialist within office hours. Usually it will be possible to speak to them within 24 to 48 hours. If your child's consultant is not in the hospital, another immunology doctor is always available for urgent problems. Contact details are given at the end of this information sheet.

Day case admissions

Occasionally, your child may need to come to the hospital for a day to have investigations, see other specialists, or receive some treatment. If there are too many tests and/or consultations to fit into one day, we may arrange for you and your child to stay in bed and breakfast accommodation nearby and come to the hospital during the day. These visits are likely to take place on Safari Day Care unit.

During such a visit, you and your child will usually be seen by an immunology nurse specialist and their named consultant, and sometimes by one of the registrars or senior house officers. You will usually be sent a plan of the day(s) beforehand outlining the timetable of investigations and consultations.



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Inpatient stays

If your child needs to be admitted to GOSH as an inpatient, this will usually be to the immunology ward (Robin Ward, Fox ward, Pelican Ward), although occasionally other wards are used. He or she will be cared for by the ward nurses and the team of doctors responsible for the ward at that time.

The consultant responsible for care of children on the ward (the 'attending consultant') usually changes each month, with five consultants taking part in the rota. Day to day decision-making and discussions with you will be the responsibility of the attending consultant. However, important decisions always involve discussions with your child's named consultant, who obviously knows your child's background best. Meetings with you may sometimes involve both the attending consultant and your child's own consultant.

If your child needs to be in hospital for a long period, the attending consultant may change several times. At the end of each month, a handover ward round takes place involving both the outgoing and the incoming consultant. This gives you a chance to be introduced to the new doctor and ensures that they receive all necessary information about your child. However long your child's stay in hospital, their own consultant will continue to be involved in management 'behind the scenes', and once your child is discharged they will return to the outpatient care of that consultant.

While they are an inpatient, your child will be seen by the ward medical team at least once a day, and often more than once. The attending consultant visits the ward every day to discuss all the patients with the ward doctors and nurses, and formal consultant ward rounds take place twice a week. Extra meetings to discuss your child's progress can also be arranged at other times. We will keep you fully informed of your child's progress, and will always discuss with you any changes in treatment or care before such changes are made.

Investigations

It is very likely that your child will need tests at various times, both to establish the diagnosis and to monitor their progress. Most of these will be blood tests and X-rays, but sometimes more complicated tests are needed that may require sedation or an anaesthetic. We will give you information about individual procedures, and we will always explain about any possible risks or complications. For some investigations we may ask you to sign a consent form giving permission for your child to have them.

Research

GOSH is actively involved in many aspects of research, which is aimed at improving the care and outlook of this and future generations of children. You may be asked for permission for your child to participate in these studies while they are under the care of GOSH.

This may include permission to take extra blood or tissue samples – either to be stored in case they are needed for research or diagnostic tests in the future, or for research currently taking place. The researcher will always explain such studies fully to you and also give you an information sheet. We will always ask for your consent.



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You do not have to agree to let your child take part in these studies, and refusal would not in any way affect the care and treatment that your child receives. If you do agree for your child to take part in a research study, you are free to withdraw them from it at any time. Any blood or tissue samples for research purposes would almost always be taken at the same time as a procedure which your child is having anyway.

Further support and information

There are a number of support groups offering support and advice to anyone affected by an immunology disorder or condition. Here are contact details for a few of the main ones. You can also contact the umbrella organisation for support groups in the UK at Contact a Family. Ring their helpline on 0808 808 3555 or visit their website at [Contact - for families with disabled children | Contact](#)

- **Immunodeficiency UK** – ring their helpline on 0800 987 8986 or visit their website at [Immunodeficiency UK - Immunodeficiency UK Home page](#)
- **Max Appeal** offers support and advice to anyone affected by DiGeorge syndrome, Velo-Cardio-Facial Syndrome (VCFS) and 22q11.2deletion syndrome. Call their helpline on 0300 999 2211 or visit the website at www.maxappeal.org.uk
- **A-T (Ataxia Telangiectasia) Society** – ring them on 01582 760 733 or visit their website at www.atsociety.org.uk
- **CGD (Chronic Granulomatous Disease) Society** – ring their helpline on 0800 987 8988 or visit their website at www.cgd.org.uk

Information sheets

A wide variety of patient and family information leaflets is available. You can ask staff in the Immunology Department about these. Most of our leaflets are also available on the hospital website at www.gosh.nhs.uk



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Useful numbers at GOSH

Hospital switchboard	020 7405 9200
Immunology Department	Ext 8834, Ext 5024 via Hospital Switchboard
Consultants secrétaires	Ext 8834 via Hospital Switchboard
Clinical Nurse Specialists:	Ext. 5024 via switchboard
Robin Ward	020 7829 8811
Fox Ward	020 7829 8820
Safari Day Care	020 7829 8833
Outpatient Appointments Centre	020 7829 8880
Inpatient/Day case coordinator	Ext 5024 via Switchboard
Out of hours – Call the hospital switchboard (see above) and ask for the on-call immunology doctor	

Hospital switchboard	020 7405 9200
Immunology Department	020 7405 9200 extn 5024 via Hospital Switchboard
Immunology Department fax	020 7813 8552
Consultants secretaries	020 7829 8834 (Drs Worth, Ip, Booth, Davies and Cale, Professors Gaspar, Thrasher, Qasim and Goldblatt)
Clinical Nurse Specialists:	
Immunology	Ext. 5024 or bleep 620, 563 or 776 via switchboard
Clinical Trials	Ext. 0577 or bleep 773 via switchboard
CGD	Message pager via switchboard

Robin Ward	020 7829 8811
Fox Ward	020 7829 8820
Safari Day Care	020 7829 8833
Outpatient Appointments Centre	020 7829 8880
Inpatient/Day case coordinator	020 7813 8122

Out of hours – Call the hospital switchboard (see above) and ask for the on-call immunology doctor