

# Welcome to the family clinic

This leaflet tells you more about the family clinic. Please feel free to ask our team any questions you have about the information below.

## The Multidisciplinary Team (MDT)

The team caring for your child is made up of doctors, clinical nurse specialists, psychologists, physiotherapists, dieticians and the family clinic co-ordinator, and this team will also support you. Children typically see all members of the team at some stage during their follow-up and will often see several members of the team at each appointment. Some members of the MDT may also offer individual appointments outside of routine clinic times.

## Appointments

**Medical reviews: Tuesdays 10.00-12.30 and Thursdays 10.00-12.30**

**Nurse specialist: Tuesdays 16.30-18.30 and Fridays 09.00-12.30**

Children who are stable on treatment have medical appointments at least every four months. **While we try to accommodate requests for appointments in the school holidays, priority is given to teenagers taking public exams – usually school years 11-13.** This means your child will be similarly prioritised when they reach this stage. As the majority of children attending clinic are now 13 years of age and older, it is not possible to see all children within the holidays.

At your child's routine medical appointment they will be reviewed either by a consultant or a registrar. Due to the number of children attending clinic, it is not always possible to see the same doctor, but all children will be seen by a consultant at least once a year. If you have a particular issue to discuss with a specific doctor, please tell us before your appointment and we will try to accommodate this.

**Cancellations:** To cancel an appointment please call 020 3312 6349 and speak to the co-ordinator or leave a message on the answer phone. Alternatively, you can email [familyclinic@imperial.nhs.uk](mailto:familyclinic@imperial.nhs.uk). Please try and give as much notice as possible, so another family can take the appointment slot.

## Research

All members of our team support research that aims to improve the care and long-term outcomes for children attending the clinic. Therefore you and /or your child may be invited to participate in a clinical study. This is entirely voluntary and members of the team will discuss it with you in more detail. All studies accepted in the clinic have been reviewed by the National Ethics Committee ([www.nres.nhs.uk](http://www.nres.nhs.uk)) and are run in accordance with Good Clinical Practice ([www.mrc.ac.uk/documents/pdf/good-clinical-practice-in-clinical-trials/](http://www.mrc.ac.uk/documents/pdf/good-clinical-practice-in-clinical-trials/)).

## Patient involvement

We welcome patient feedback in order to improve care. Regular patient surveys are conducted within the clinic and we thank you in advance for taking part. For children and families who would like peer support, we have strong links with: Positive UK ([www.positivelyuk.org](http://www.positivelyuk.org)), Body and Soul ([www.bodyandsoulcharity.org](http://www.bodyandsoulcharity.org)), and the CHIVA summer camp ([www.chiva.org.uk](http://www.chiva.org.uk)). Please let us know if you would like to learn more about voluntary sector services.

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## Vaccinations

These are carried out in your GP surgery. Please check that your child's vaccinations are up-to-date. If you could provide the family clinic with a yearly record this would be extremely helpful.

## Medication prescribing

Unfortunately, the family clinic can only provide medicines related to the prevention and treatment of infections. This means that you will need to visit your GP for regular repeat prescriptions such as inhalers and skin creams. If you are running out of medicines please phone the family clinic on 020 3312 6349 to arrange an urgent one month supply that you will need to collect. Further information on medication can be found at [www.i-base.info](http://www.i-base.info)

## Travel abroad

Please discuss upcoming travel with our team. If you're travelling outside of Europe, please visit your GP six weeks in advance for travel vaccines and/or antimalarial prophylaxis.

## Transition to adult care

With successful treatment, children who were once seen in the family clinic are now attending adult services. We have a dedicated service for young adults called the 900 clinic and teenagers typically transition from the family clinic to the 900 clinic between the ages of 16 and 18. The process of transition and preparation for adult care is discussed with young people and their families for several years prior to the move, to make the process as easy as possible.

## Failure to attend appointments

If you do not attend an appointment for any reason we will try to contact you by phone, email and post, using the contact details you have provided – please keep us updated of any changes. A letter will be sent confirming a second appointment. To provide the best healthcare for your child and in line with safeguarding policy, failure to attend two appointments and/or not attending clinic for more than six months due to recurrent cancellations will result in a referral to social services, to help support clinic attendance.

## How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777**. You can also email PALS at [pals@imperial.nhs.uk](mailto:pals@imperial.nhs.uk). The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf. Alternatively, you may wish to express your concerns in writing to: The chief executive's office, Imperial College Healthcare NHS Trust, Trust Headquarters, The Bays, South Wharf Road, London W2 1NY.

## Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on **020 3312 5592**.

Department of paediatric infectious diseases  
Published: January 2015  
Review date: January 2018  
Reference no: 2524  
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