

Xeroderma pigmentosum (XP) clinic

This leaflet explains more about the national xeroderma pigmentosum (XP) multi-disciplinary clinic at St Thomas' Hospital. If you have any further questions, please speak to a doctor or nurse caring for you.

What is XP

XP is a rare, hereditary skin condition where the body is not able to repair damage caused by the ultraviolet part of daylight. People with XP are more likely to burn easily or develop abnormal freckles on skin which is exposed to daylight. They can also develop eye problems due to damage from ultraviolet light. People with XP are more likely to develop skin cancers, particularly if they do not protect themselves from the harmful effects of ultraviolet light. XP can also cause problems with the nerves or brain.

Who will care for me?

The health professionals listed below have different skills and are experts in XP. They will work together to give you the best care – this is known as a 'multi-disciplinary clinic'. We are the only clinic of this type in the country for XP and we care for adults and children from across the UK. The team consists of:

- Consultant dermatologist
- Consultant neurologist
- Consultant ophthalmologist
- Consultant geneticist
- Consultant dermatology surgeon
- Clinical nurse specialist
- Clinical psychologist
- Medical photography

We work with colleagues at Sussex University to diagnose XP. We also work very closely with the UK XP patient support group. Our aim is to work with your local hospital and doctors to ensure that you receive the best care possible for your condition.

XP clinic

We hold separate, monthly clinics for children and adults, and occasional clinics for young adults. In the XP clinic, all of the health professionals listed above can see you on the same day.

- The clinics are held on Fridays and usually last all day (9am–5pm), depending on which health professionals you need to see. This will be discussed with you before you attend.
- Appointments are held in the morning and last approximately 45 minutes each.
- The afternoon is set aside for any further investigations you may need, such as skin biopsies, minor skin surgery, blood tests and photographing your skin.
- A lunch voucher is provided to buy food in the hospital restaurant between 12.30pm and 1.30pm.

- Throughout the day, you are encouraged to ask any questions you may have about XP.
- You can also choose to meet with someone from the XP support group in the clinic.
- After your appointment a letter will be sent to you and your local health team summarising your visit.

Who can use the service?

Anyone who has been diagnosed with or is suspected of having XP can use this service.

You will need to be referred to us by your local hospital doctor. An XP nurse specialist will then contact you with an appointment date, and give you the opportunity to ask any questions you may have about the day.

Where do I need to go?

The clinics are held at St Thomas' Hospital in London. A letter with information on where in the hospital you will need to go will be sent to you.

Travel details to the hospital can be found at www.gstt.nhs.uk along with information about what to do if you qualify for help with travel costs. If you do not qualify for this, the XP Support Group may be able to help towards travel or overnight stay costs if needed – you can contact them by email on info@xpsupportgroup.org.uk. If you want to ask the XP Support Group for help, please contact them as early as possible.

What do I need to bring with me?

- If this is your first time at the clinic please bring photographs of yourself from an early age, as these can help us to assess the skin and how it has changed over time.
- Glasses (if normally worn).
- A list of any current medication you are taking, including those you get from your doctor on prescription, medicines you have bought for yourself and any alternative medicines, such as herbal remedies.
- Some people find it helpful to write down any questions they would like to ask.
- Child health record (red book).
- If you are bringing your child to the clinic, a school report or records can help us assess your child.
- Details from local clinic, hospital or community appointments, including developmental clinics and hearing tests if available.

Outreach visits from XP nurse specialists

The XP nurse specialist is available to visit you (or your child) at home, school or work.

The nurse can advise on photo protection (how to keep safe from ultraviolet light) and can act as a link between hospitals and home.

Please contact the XP nurse if you are interested in receiving a visit (see the 'contact us' box below for contact details).

Useful sources of information

XP Support Group – offers advice and practical help to anyone affected by XP.

t: 01494 456 192

e: info@xpsupportgroup.org.uk

w: www.xpsupportgroup.org.uk

Directgov – to find out if you may qualify for benefits or assistance at school.

w: www.direct.gov.uk

Contact us

If you have any questions or concerns about XP, please contact the XP nurse specialists on **020 7188 6339** or **020 7188 6351** (Monday to Friday, 9am to 5pm). Out of hours, please leave a message on the answer phone with your contact details and someone will get back to you.

Alternatively, you can email Sally Turner (children's XP nurse specialist) on **sally.turner@gstt.nhs.uk**.

Patient Advice and Liaison Service (PALS) – To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Language support services – If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS Choices – Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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