Inherited Metabolic Disease Service
Patient Information
Lysosomal Clinic

Authors
Liz Morris/Patrick Deegan

Pharmacist
N/A

Department
Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ
www.cuh.org.uk

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01223 274634

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Contact us
LDU Box 135, Addenbrooke’s Hospital, Hills Road, Cambridge. CB2 0QQ
Tel: 01223 274634
Email: lducambridge@nhs.net

www.cuh.nhs.uk/addenbrookes-hospital/services/lysosomal-disorders

Please note the department is open Monday to Friday 08:30-17:00.

If you are unwell outside of these hours you should seek medical advice from your local healthcare team.

If your emergency doctor needs specific advice they should call the hospital switchboard on 01223 245151 and ask for the metabolic consultant on call.

If you would like this information in another language or audio, please contact Interpreting services on telephone: 01223 256998, or email: interpreting@addenbrookes.nhs.uk

For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.
This leaflet is designed to welcome patients and families to the Lysosomal Disorders service at Cambridge University Hospitals (CUH).

About us
The lysosomal disorders service is one of the UK’s national specialist centres for the diagnosis, assessment and management of patients with lysosomal disorders.

Lysosomal storage disorders are a group of rare inherited diseases caused by single gene defects and there are currently thought to be at least 70 different disorders. The symptoms experienced by patients are variable and can affect many different parts of the body.

The clinical team consists of:
- Consultant metabolic physicians
- Clinical nurse specialist
- Metabolic dieticians
- Metabolic pharmacist
- Metabolic psychologist
- Administrative staff
- Research team

You may also need to be seen by other departments in the hospital for investigations and/or clinical advice which will be discussed with you at your clinic appointment.

Usually clinics are held in the afternoons, to allow you time to get to Cambridge, and are often disease specific.

Monday: Gaucher
Tuesday: Fabry
Wednesday: Other lysosomal storage disorders

Wherever possible all other tests and investigations will be booked for the same day.

Please note that in order to accommodate each person’s clinical needs the clinic you attend may not be dedicated solely to your disorder.

You should receive a clinic letter within a day or so of your visit, with a further letter three weeks later containing your test results.

Attending the clinic
Please:
- Bring a list of your current medication and any completed questionnaires.
- Allow plenty of time for your visit to the clinic and any other appointments you may have on the same day.
- Let us know in advance if you are unable to attend.
- Provide feedback on your experience using the feedback forms available in the clinic.

You are welcome to bring a friend/relative with you, but please be aware space is limited. Please contact the department if you are concerned about this.

CUH is a teaching hospital. With your permission, medical students or other trainees may attend the consultation.

Finding us
The department is located in the R block on the ground floor, between wards R2 and rehabilitation. Please ask for directions from the hospital volunteers if you have any difficulty.

For help with finding your way to or around the hospital please visit the CUH website: https://www.cuh.nhs.uk/addenbrookes-hospital/finding-us

For help with travel costs please ask for a leaflet in clinic or visit the CUH website https://www.cuh.nhs.uk/finding-us/help-with-travel-costs

We are sometimes able to provide overnight accommodation in Pemberton House for patients travelling significant distance – please ask the clinic staff for more information.