



University Hospitals  
Birmingham  
NHS Foundation Trust

# INHERITED METABOLIC DISORDERS



Centre for  
Rare Diseases

Patient Information Leaflet

[www.uhb.nhs.uk/crd-inherited-metabolic-diseases.htm](http://www.uhb.nhs.uk/crd-inherited-metabolic-diseases.htm)

The Inherited Metabolic Disorders (IMD) service at University Hospitals Birmingham NHS Foundation Trust is based in the Centre for Rare Diseases in the Heritage Building (original Queen Elizabeth Hospital). It provides a clinical service for the diagnosis, assessment and treatment of adult patients with Inherited Metabolic Disorders.

We are a multi-disciplinary team led by IMD consultants alongside specialist dietitians, nurses, pharmacist, physiotherapist, IMD Service Coordinator, clinical psychologist, welfare officer, research nurse and secretary. The service is fully supported by other specialties including heart, liver, kidney, neurology and genetics. The adult IMD service is closely linked to Birmingham Women's and Children's Hospital (BWCH) IMD unit.

We look after adult patients from across the Midlands and South West England with Inherited Metabolic Disorders, including; carbohydrate, amino acid and fatty acid metabolism disorders, lysosomal storage diseases, mitochondrial diseases, organic acidaemias, urea cycle disorders and lipid disorders.

## Contacting the team

We are available during normal working hours (08:00–16:00) to answer questions about your condition and to provide you with general support and advice. To speak to a member of the team, the best time to call is on Monday to Friday 08:00–16:00 via the secretary Lindsey Fletcher-Jennings.



## IMD Consultants

**Professor Tarek Hiwot**  
Consultant in IMD

**Dr Charlotte Dawson**  
Consultant in IMD

## Medical Secretary/PA

**Lindsey Fletcher-Jennings**

 [uhb-imdteam@uhb.nhs.uk](mailto:uhb-imdteam@uhb.nhs.uk)  
 0121 371 6987

If you have any questions for the consultants, please contact the Team's Secretary, Lindsey Fletcher-Jennings, who will be able to assist.

## Specialist Nurses

**Sarah Steeds**

 [imdurses@uhb.nhs.uk](mailto:imdurses@uhb.nhs.uk)  
 0121 371 6986  
 07766 421 855

**Sandra Munyoro**

 [imdurses@uhb.nhs.uk](mailto:imdurses@uhb.nhs.uk)  
 0121 371 6776

## Specialist Dietitians

**Louise Robertson,  
Sarah Howe, Clare Dale and  
Leah Roberts** (Dietetic Assistant)

 [imddietitians@uhb.nhs.uk](mailto:imddietitians@uhb.nhs.uk)  
 0121 371 6989  
 07799 038 656

## Pharmacy@QEHB

If you get regular medication dispense by us

 0121 371 5479 / 0121 371 5480

## Consultant Pharmacist

**Antonio Ochoa-Ferraro**

 [antonio.ochoa-ferraro@uhb.nhs.uk](mailto:antonio.ochoa-ferraro@uhb.nhs.uk)  
 0121 371 6798  
 07766 504 437

## IMD Service Coordinator

**Kelly Watkins**

 [imdteamqehb@uhb.nhs.uk](mailto:imdteamqehb@uhb.nhs.uk)  
 0121 371 6984

## Specialist Nurses

**Vishy Veeranna**

 [vishy.veeranna@uhb.nhs.uk](mailto:vishy.veeranna@uhb.nhs.uk)  
 0121 371 6694  
 07766 505 129

**Rebekha Del Gaizo**

 [rebekah.delgaizo@uhb.nhs.uk](mailto:rebekah.delgaizo@uhb.nhs.uk)  
 0121 371 6696

## Physiotherapists

**Nicola Condon**

 [nicola.condon@uhb.nhs.uk](mailto:nicola.condon@uhb.nhs.uk)  
 0121 371 6987

**Rachel Curran**

 [rachel.curran@uhb.nhs.uk](mailto:rachel.curran@uhb.nhs.uk)  
 0121 371 6987

# One-Stop Clinic

Adults with Lysosomal Storage Disorders are offered a multi-disciplinary 'one-stop' clinic. The aim of the one-stop clinic is to concentrate necessary tests and clinical appointments into a single visit, usually lasting a whole morning, but occasionally requiring two separate visits on consecutive days. The frequency of the one-stop clinic is individually tailored to each patient and might vary between once a year to once every three years, with interim clinical appointments midway between the one-stop visits.

During your one-stop visit you may need to move between the Centre for Rare Diseases and the main hospital for your tests and appointments. If you require a wheelchair to take you between appointments, please let the team know before you arrive, so that we can make arrangements to acquire a chair and, if required, someone to accompany you. If you need adaptations, again, please let us know in advance of the clinic.

When you are booked on to a one-stop clinic, you will be advised of your individual test appointment times by the departments in which they occur.

Testing is individually tailored to each patient by the Consultants, so your personal schedule may vary from year to year. Please be aware that the actual appointment times for each test may change on the day depending on how busy the test department is. If you are delayed we ask that you contact the IMD co-ordinator using the number on your schedule to ensure that you don't miss your medical appointments. You can call from any of the desks in the out-patients department.



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**For general enquiries please call  
Lindsey Fletcher-Jennings on:**

**0121 371 6987**

Please note this is not an emergency helpline.

If you feel unwell please contact either your IMD Nurse or Dietitian during working hours using the contact details overleaf. They will advise on how to manage your condition at home or whether you need to come into hospital, and will discuss your problem with one of the consultants who can call you back if necessary.

In case of extreme emergency, please call an ambulance or attend the Emergency Department with a copy of your emergency regime (if required). Out of hours, please call the hospital switchboard on 0121 371 2000 and ask for the Inherited Metabolic Consultant on call.

We are continually trying to improve the service we offer to patients and always welcome informal feedback. You can offer feedback by phoning/emailing the clinic co-ordinator Kelly Watkins on

 0121 371 6984

 [imdteamqehb@uhb.nhs.uk](mailto:imdteamqehb@uhb.nhs.uk)

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Heritage Building  
Mindelsohn Way, Edgbaston  
Birmingham B15 2GW

