

INHERITED METABOLIC DISORDERS



Centre for
Rare Diseases

For general enquiries please call the secretary 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 usual working hours please contact the IMD consultants via hospital switchboard (0121 627 2000).

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 Liz Wadsworth on

☎ 0121 371 6984

✉ liz.wadsworth@uhb.nhs.uk

Adult Inherited Metabolic Disorders Service
Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston
Birmingham B15 2GW

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Patient Information Leaflet

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, IMD co-ordinator, psychologist, welfare officer, research nurse and secretary. The service is fully supported by other specialties including heart, liver, kidney, neurology, genetics, ophthalmology, audiology and rehabilitation services. The adult IMD service is closely linked to Birmingham Children's Hospital (BCH) IMD unit.

We look after adult patients from across the Midlands and South West England with Inherited Metabolic Disorders, including carbohydrate, amino acid and fat 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 (8am – 4pm) to answer questions about your condition and to provide you with general support and advice. If you wish to speak to a member of the team, the best time to call is on Monday, Wednesday or Thursday mornings when we do not have clinics.

IMD Consultants

Dr Tarek Hiwot
Consultant in IMD

Dr Charlotte Dawson
Consultant in IMD

If you have any questions for the consultants please call one of the nurses, who will get back to you as soon as possible.

Specialist Nurses

Sarah Steeds
✉ sarah.steeds@uhb.nhs.uk
☎ 07766 421 855
☎ 0121 371 6986
✉ imdnurses@uhb.nhs.uk

Helen Gallagher
✉ helen.gallagher@uhb.nhs.uk
☎ 07766 441 159
☎ 0121 371 6985
✉ imdnurses@uhb.nhs.uk

Specialist Dietitians

**Louise Robertson, Sarah Howe
Clare Dale**
✉ imddietitians.uhb@nhs.net
☎ 07799 038 656
☎ 0121 371 6989

Specialist Pharmacist

Antonio Ochoa-Ferraro
✉ antonio.ochoa-ferraro@uhb.nhs.uk
☎ 0121 371 6798

Welfare Officer

Stuart Hill
✉ shill@aurigaservices.co.uk
☎ 07983 819 899

Psychology

Dr Anne-Marie Walker
✉ imdteam@uhb.nhs.uk
☎ 0121 371 6987 (Secretary)

IMD Co-ordinator

Liz Wadsworth
✉ imdteam@uhb.nhs.uk
☎ 0121 371 6984

Research Charge Nurse

Vishy Veeranna
✉ Vishy.veeranna@uhb.nhs.uk
☎ 07766 505 129
☎ 0121 371 6694

Physiotherapist

Nicola Condon
✉ Nicola.Condon@uhb.nhs.uk
☎ 0121 371 3489

One-Stop Clinic

Adults with lysosomal storage disorders are offered a once-yearly multi-disciplinary 'one-stop clinic'. The aim of the one-stop clinic is to concentrate necessary annual tests and clinical appointments into a single visit usually lasting a whole morning, but occasionally requiring two separate visits on consecutive days. Most patients also have an interim clinical appointment mid-way between their 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. The IMD co-ordinator will also send you a summarised schedule of all of your appointments along with directions and maps.

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 dept.

Lunch vouchers will be provided by the IMD clinic co-ordinator if your appointments overrun into late morning/afternoon.

