

# Inherited metabolic diseases (IMD) team

## Welcome to the IMD team

This leaflet explains who the key people involved in your child's care are. It also explains what they do and how you can contact them. The metabolic team includes lots of different staff, with different roles.

We can all help you in different ways, and can be called for support and advice if you need it (contact details at the end of this booklet).

**If your child is unwell and you are concerned and cannot speak with someone from the team immediately, seek medical advice from your GP or go to your nearest Emergency Department (A&E).**

## The IMD team

### Consultants

The consultants are specialists in metabolic medicine and will be the main doctor in charge of your child's metabolic care. They will manage your child's care until they are discharged from our care, or transition into the adult services when they reach 16. You will see the consultant at regular clinic appointments, either at the Evelina London Children's Hospital or in one of our clinics in the community.

If your child becomes unwell and needs hospital admission to your local hospital, the metabolic consultant on call will be told and will support the management of your child's care. Please call us to let us know that your child has been admitted.

## **Administration team**

The administration team support the consultants and can be contacted if you:

- need a copy of a clinic letter if you have lost or not yet received it
- need to follow up any non-dietetic blood results
- have a query about an appointment which cannot be resolved via the appointment centre
- need to update any of your personal details, such as address, GP or contact numbers

## **Nursing team**

The clinical nurse specialist (CNS) team can help you in managing and understanding your child's condition.

They can advise you what to do if your child is unwell at home, give telephone advice, and liaise with your local hospital if needed.

They can contact your child's nursery or school before they are due to start, to tell them about your child's metabolic condition and any particular management that they might need. For example, a special diet or what to do if your child becomes unwell.

Your child's nurses can help with:

- advice during illness and support with 'emergency regime'.
- condition management at nursery or school
- accessing financial support
- social, emotional and community support
- medicine doses and supplies
- advice about going on holiday with medicine
- referrals to local services, including community nursing teams

## **Dietetic team**

The specialist dietetic team can help you manage your child's metabolic diet. They can also help with any issues you have with dietary products and supplements.

Your dietitian can help with:

- specialist 'emergency regime' during illness (which interim recipes to use and when)
- specialist weaning advice (specialised, restricted metabolic diets)
- specialist prescription foods and supplements
- blood spot results
- blood spot testing equipment
- letters for going on holiday with feeds and emergency regimes

## **Appointment centre**

We have a dedicated team that manage our outpatient appointments. Letters are usually sent to you 6 weeks before the appointment date. Please contact the appointments team if you:

- cannot come to the appointment
- would like to reschedule
- notice any errors with your appointment

## **Savannah Ward**

If your child needs admitting to hospital, they will probably be on Savannah Ward. The admission can be planned (elective) or might be an emergency transfer from your local hospital to Savannah Ward. This ward cares for children with both neurological (nervous system) and metabolic conditions, and is on the 4<sup>th</sup> Floor.

Please do not come directly to Evelina London Emergency Department (A&E) unless you have been told to. You will need to present to your local hospital first.

If an elective admission is needed, you will be contacted by our admissions co-ordinator and further details of the ward will be given to you. Please note that:

- only **1** parent can stay on the ward overnight
- **no** siblings can stay on the ward overnight
- food is **only** provided for patients and breastfeeding mothers

## Who to call

If your child is unwell or you are concerned about them, contact the CNSs. They can advise you how to manage your child's illness.

If your child has a specialist metabolic diet that requires an emergency regime, or an interim regime and they need changes to their diet during illness (such as MSUD, organic acidaemias), call the metabolic dietitians.

Outside of office hours, please contact the paediatric metabolic on-call registrar.

## Travelling to hospital

There are different ways to get to Evelina London. Please visit our website for more information, **web:** [www.evelinalondon.nhs.uk/parents-and-visitors/getting-here/directions.aspx](http://www.evelinalondon.nhs.uk/parents-and-visitors/getting-here/directions.aspx)

Please note that the hospital is in the Congestion Charge zone. Parking is available at the hospital, but is limited and there is a charge. There are a limited number of allocated disabled bays for parking with an authorised Blue badge. You will need to show an appointment letter to use these bays.

## Claiming for your travel

Some patients can claim part or full repayment of travel costs to and from hospital if they are receiving one of these benefits and allowances:

- Income Support
- Income Based Employment and Support Allowance
- Income Based Job Seekers Allowance
- Working Tax Credit and Child Tax Credit.

If you have any queries, please contact the St Thomas' Cashier's Office, **tel:** 020 7188 2328, or go to, **web:** [www.guysandstthomas.nhs.uk/resources/patient-information/all-patients/transport-travel-costs-help.aspx#na](http://www.guysandstthomas.nhs.uk/resources/patient-information/all-patients/transport-travel-costs-help.aspx#na)

Cashier's Office opening hours:

	Morning	Afternoon
Monday to Thursday	9.30am to 2pm	2.30pm to 4.30pm
Friday	9.30am to 2pm	2.30pm to 4.15pm

## Useful information

**Metabolic Support UK**, supporting families affected by IMD. Offering information, family contact and advice services, fundraising support, conferences, workshops and education days, **web:** [www.metabolicsupportuk.org](http://www.metabolicsupportuk.org)

## Notes

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## Contact us

During office hours, Monday to Friday, 9am to 5pm:

### Appointment centre

**tel:** 020 7188 4000, **email:**

PaediatricAppointmentsMetabolic@gstt.nhs.uk

### Consultants' secretaries

**tel:** 020 7188 0848

**Nursing team, tel:** 020 7188 0855

**Dietetic team, tel:** 020 7188 4008

**Savannah Ward, tel:** 020 7188 8848

For urgent enquiries outside office hours, please call switchboard, **tel:** 020 7188 7188, and ask for the paediatric metabolic on-call registrar. They will be able to liaise with the on-call consultant about your child's care.

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web:** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

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