

Inherited Bleeding Disorder (IBD) Team

Introduction to the Inherited Bleeding Disorders Service.

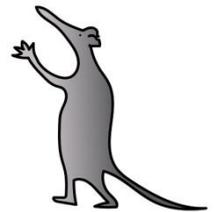
Information for Patients and Carers

Introduction

This leaflet is designed to introduce the IBD (Inherited Bleeding Disorder) team to you and explain how to access the services we provide.

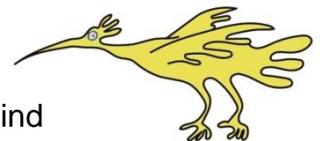
Telephone Numbers you may need

Alder Hey (switchboard)	0151 228 4811
Direct Dial Nurse Specialists Office (with answer machine)	0151 252 5070
Nurse Specialist Mobile (in working hours)	07584 234 526
Ward 3B Inpatients ward (out of hours advice)	0151 252 5212
Consultant Secretary:	0151 252 5824
Haematology Treatment Room In outpatients floor 2.1	0151 228 4811 ext. 3822
Physiotherapy Reception	0151 252 5430
Ward 3B Daycare	0151 293 3684
Accident and Emergency	0151 252 5035



The IBD Team

IBD Nurse Specialist:	Sharon Thind
IBD Associate Nurse Specialist:	Rebecca Rogers
Consultant Haematologists:	Dr Jessica Sandham Dr Russell Keenan Dr Banurekha Thangavelu
Haematology Admin Assistant:	Annie Quirk
Quality Project Manager	Jacqui Hale
Specialist Physiotherapist	Dave McWilliam



Where to find us

Clinic Appointments

These can be held in one of 4 places, please read your clinic letter carefully for the destination

- Consultant Led Clinic for new patients/referrals...3B clinic on inpatient side of hospital (use lifts behind concierge desk)
- Consultant Led Annual Review Clinics...Outpatient Dept level 1.2 (use lifts behind Costa Coffee)
- Nurse Led Clinics/Reviews...Outpatient Dept level 2.1 (use lifts behind Costa Coffee)
- Physiotherapy Review...Outpatient Dept lower ground level (use lifts behind Costa Coffee)

Drop-In Reviews

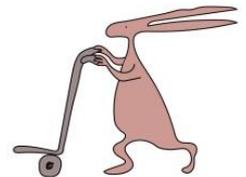
Your IBD drop in service is located in the Outpatient Department Level 2.1 which is located in the Outpatient area of the Trust on the 2nd floor behind Costa Coffee. Some outpatient appointments and any planned or unplanned treatments will happen in this area.

The drop in service is generally available between **8am and 5pm, Monday – Friday**

NB: Please phone ahead to let the nursing team know you are on your way in so preparations can be made if necessary, a suitable time can be arranged or on the rare occasion when no one is available other arrangements can be made

The drop in service is for

- Reviewing your child (may include blood sampling)
- Giving advice or treatment
- Referring on to appropriate services
- Answering queries and talking through worries



Clinics

Why come to clinic?

It is very important that you attend your child's clinic appointment. Clinic appointments give the IBD team the opportunity to assess your child and to ensure that they have no problems with their treatment and other aspects of care.

If your child is on any medication or treatment these will be monitored in clinic and any changes to treatment decided.

Clinic also gives you the opportunity to ask questions, get information and support on how to care for your child. Once a year your child will have a full annual review in a designated clinic and any new developments or treatments can be discussed.

You must keep your appointments even if your child seems to have had no problems. This is the opportunity to assess children when they are well and to ensure that we have the right treatment plan in place. Please aim to turn up for your clinic appointment on time making allowances for finding a parking space.

How do I change a clinic appointment or what do I do if I can't come to clinic?

Ring the Haematology Admin Team on 0151 252 5824, as soon as you know that you cannot attend, so that the appointment can be rearranged.

How often does my child need to come to clinic?

Most children will be seen in clinic every 3-12 months.

Your child may also be given an extra clinic appointment when they are discharged from the ward following an admission

What should I do if I want an appointment earlier than planned?

Sometimes you may have questions, non-urgent concerns about your child or other issues that you want to discuss with a doctor or nurse specialist. You can ask for a clinic appointment to do this by calling the Haematology Admin Team on **0151 252 5824** and they will be able to organise a clinic appointment for you.

If your child is unwell and you want to see a doctor straight away then you may be asked to bring them to accident and emergency.

What will happen at clinic?

Depending on the location of your appointment please use the following instructions:

For Level 1.2 or 2.1 Outpatients

When you arrive at the hospital you should book in on the electronic system in the Atrium, when it is time for you to come to clinic a digital on screen announcement will be made for you to go to level 1.2 or 2.1. Please report to reception staff to let them know that you have arrived. Please arrive on time for your appointment

For 3B Outpatients

If your appointment is on 3B you will need to go directly to the outpatient department waiting area. Please report to reception staff to let them know that you have arrived. Please arrive on time for your appointment.

Your Appointment

Your child will be called for height and weight measurements before you see the clinician.

In your appointment we will discuss how you and your child are managing their bleeding disorder. We will ask about any achievements and any difficulties or problems. We will also ask about school and activities and discuss treatment options. We may then need to carry out some blood tests.

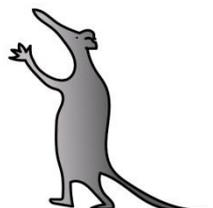
If required you may also visit the specialist physiotherapist in the physio department.

Who will I see in clinic?

In clinic you will see a Consultant Haematologist, Specialist Registrar or a nurse specialist, and associate nurse specialist. We will ask if you agree to a medical, dental or nursing student staying in the room for the appointment. This is part of their training, but you can tell us if you would prefer them not to be in the room. You may also see the physiotherapist either in the clinic room or in the physiotherapy department.

What if I need an interpreter?

If you need an interpreter to help you with your clinic appointment please let us know before your clinic appointment and an interpreter will be provided for you. This may be virtual (LanguageLine) or an in-person interpreter.



Where to go if your child is unwell

If your child becomes unwell and you have been unable to contact any of the IBD Team you should attend the Emergency Department. Please ensure that you take any medication you have with you.

Out of hours

If you are worried about your child please contact the IBD Team on the numbers provided.

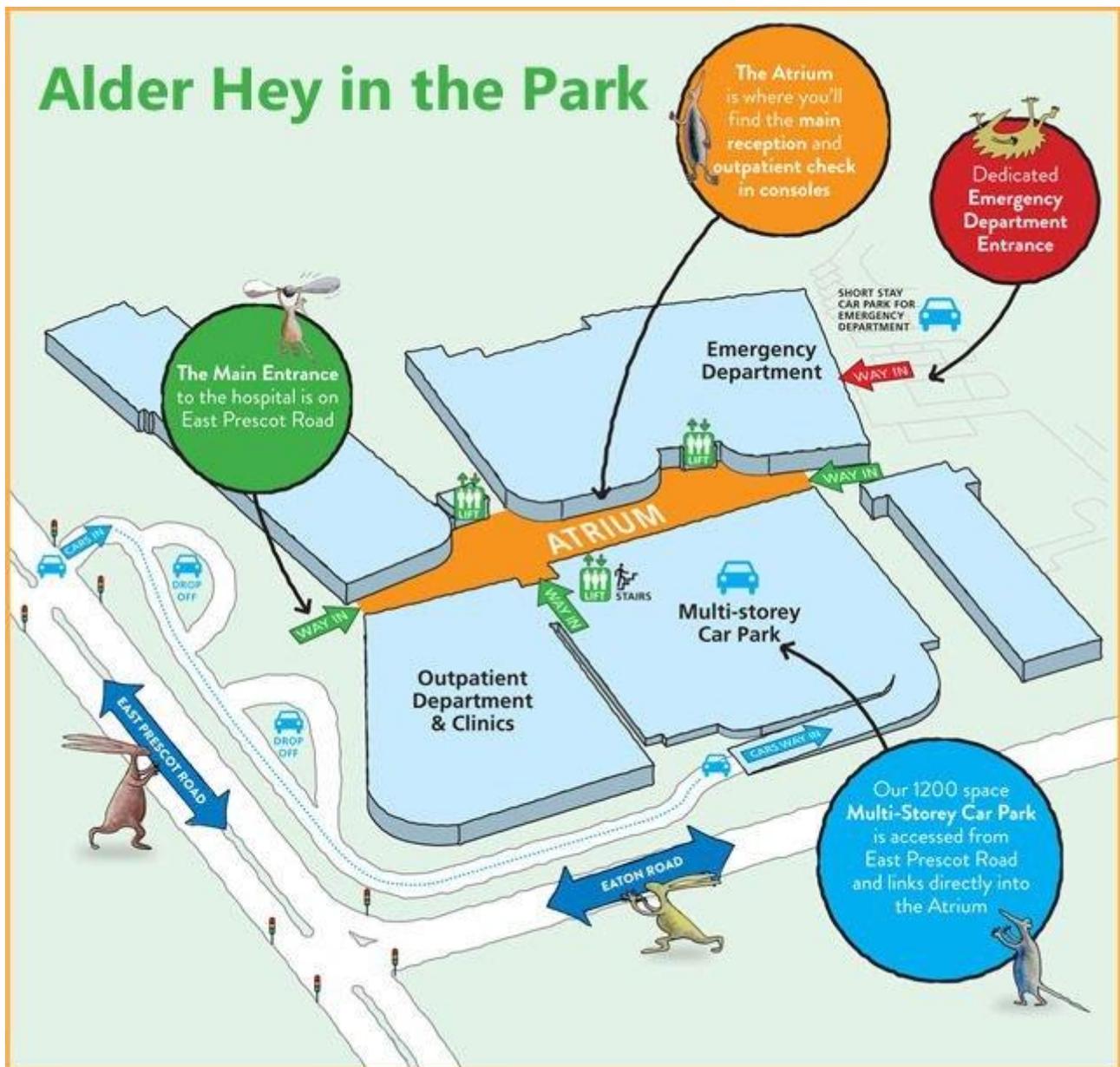
However, if it is out of hours and you have been unsuccessful please do not wait at home for a response but attend the Accident and Emergency Department. Make sure you tell them on arrival that your child has an IBD.

What to do in an emergency

Ring 999 and if necessary they will take you to the closest hospital.

On arrival at A&E tell the triage nurse and the doctor of your child's condition. In Alder Hey your child will have a care plan on the computer system informing the doctors about your child's current medication, usual treatment and any other significant issues. Remember to take any medications along with you.

Accident and Emergency



Inpatient & Daycare stays?

Should your child require admission to hospital, the IBD team will be advised and Ward 3B will most likely be the ward that your child will be admitted to if unwell or needing treatment. It could also be a surgical ward if your child needs a procedure. The team will visit your child on the daily ward round and the hospital Meditech system will allow the specialist team to keep up to date with your child's progress.

Under Current COVID Rules

Currently the hospital has a policy of only one parent to accompany the child, with no siblings allowed to visit. If this is an issue this can be discussed with the ward manager.

Community Staff

If a treatment plan is to be continued for a few days (for example intravenous antibiotics) the community team may come to your home to continue the course. The team will be introduced to you whilst you are an inpatient.

IMPORTANT REMINDER

Please tell us if you change your address, phone number, family doctor or if you are moving to another area

What services does the Inherited Bleeding Disorders Team offer?

Inherited Bleeding Disorders are life-long conditions. The Haematology team aims to help and support you and your family live as normal lifestyle as possible. There are a variety of services available to you.

Registration with the National Haemophilia Database (NHD)

The NHD is a register of people in the UK with all types of IBD. Its purpose is to improve care. When your child has been diagnosed with an IBD we will give you an information leaflet to read about the NHD. If you have any objections to your child being added to the database please discuss this with the Haemophilia Team.

Support

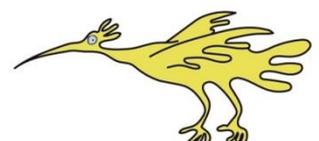
The team are here to provide support, advice, education and training. We want families to live as independently as possible. The diagnosis of a lifelong bleeding disorder may necessitate some adjustments which could possibly cause some anxieties or concerns within the family, we can make arrangements to discuss any concerns that you may have.

Information

We have a selection of written information available on haemophilia and bleeding disorders targeted at all age ranges. Please ask if you feel that you, your child, another family member, teacher etc., would like some information.

Education & Training

To help you live independently with a bleeding disorder we will help you learn more about the condition and the signs and symptoms to look out for. This might be about the appropriate time to come up for advice and to practice how to administer treatment including injections. We realise that this may be a new experience for some and we are keen to work together in order to allow independence. Our aim is that you should feel independent, but not isolated.



Benefits & Advice

The Specialist Nursing team can offer advice and direct you to services that can help you further with these issues.

Home Visits

It is often easier for us to talk with you at home without the interruption of other activities or events in the Hospital. Home visits are an opportunity for you to talk in more depth about your child's disorder, or about any issues or concerns you may have. A visit at home could be more convenient for you or other family members who may not be able to attend hospital but have questions to ask. It is also a good place for us to meet you to give you education and training on how to give medication. We may phone you to ask if we can visit you at home. To arrange a visit contact the Specialist Nurses.

School / Nursery Visits

School visits can be offered at your child's school both in person and virtually. These visits enable us to support the information you have given already and encourage them to contact us if they have any concerns. You are welcome to join us at the school or nursery visit or we can go alone.

The visits are important to help the staff to understand your child's disorder and to work appropriately with them. If you are having problems with your child's school, for example, they don't understand your child's condition, have worries about it, or your child has been excluded from certain activities, the Nurse Specialist can visit the school and talk through their concerns.

Annual Activities

In the past we have run a number of activity based events which aim to support parents and children alike. These range from small group sessions helping the children to learn about their disorder and how to give treatment to parents having the opportunity to meet while their children join in sporting activities or party games. We are hoping to return back to this once it is safe to do so.

Share your Experience

We like to know what you and your child think of the service that we are providing for them. There are a few ways in that you can feedback your views.

Patient Satisfaction Survey

Every year we will send you a questionnaire to fill out asking you and your child's opinion on different parts of the service. This may be done at your clinic visit.

Patient Stories

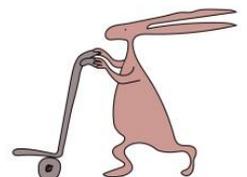
From time to time your child may be asked to write a story or draw a picture, if they would like to, about an experience they have had at Alder Hey. This can be a positive or negative story.

PALS (Patient Advice and Liaison Service)

If you have any concerns or suggestions about improving the current service you receive you can contact PALS who will make sure that your issues are raised.

You can visit them in the Atrium near the Treehouse from 9.00am to 4.00pm, Monday to Friday.
Or you can:

- Email pals@alderhey.nhs.uk
- Call 0151 252 5374 or 0151 252 5161.
- Write to: PALS, Alder Hey Children's NHS Foundation Trust, East Prescott Road, Liverpool L14 5AB.



Further Information

If you have any questions or want any further information please contact your IBD team on 0151 252 5070.

Useful websites

www.alderhey.co.uk

www.haemophila.org.uk

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this fact sheet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

Alder Hey Children's NHS Foundation Trust
East Prescot Road
Liverpool
L14 5AB

Tel: 0151 228 4811

www.alderhey.nhs.uk

