

Inherited Bleeding Disorders (IBD) Team
Inherited and Acquired Bleeding Disorders
Information for Parents and Carers

Introduction

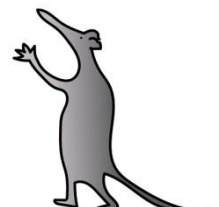
This leaflet is designed to introduce the Inherited Bleeding Disorder (IBD) Team to you and explain how to access the services we provide.

Telephone Numbers you may need

Direct Dial Nurse Specialists Office (with answer machine)	0151 252 5070
Haematology Treatment Room In outpatients floor 2.1	0151 228 4811 ext. 3822
Outpatients Reception floor 2.1	0151 252 5353
Physiotherapy Reception	0151 252 5430
Nurse Specialist Mobiles	07584 234 526 07876 132 163
Ward 3B Inpatients ward	0151 252 5212
Ward 3B Daycare	0151 293 3684
Alder Hey (switchboard)	0151 228 4811
Accident and Emergency	0151 252 5035
Consultant Secretaries:	0151 293 3680

The IBD Team

IBD Nurse Specialist:	Nicki Mackett Cathy Benfield
IBD Associate Nurse Specialist:	Rebecca Rogers
Consultant Haematologists:	Dr Mark Caswell Dr Russell Keenan Dr Banurekha Thangavelu Dr Andrew Will
Haematology Admin Assistant:	Annie Quirk
Specialist Physiotherapist	Dave McWilliam



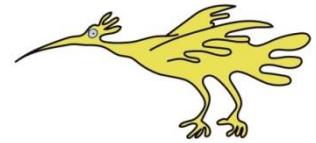
Where to find us

Your IBD clinic and drop in service are located on Outpatient Department Level 2.1, which is located in the Outpatient area of the Trust on the 2nd floor behind Costa Coffee. Outpatient appointments and any planned or unplanned treatments will happen in this area. Consultant led appointments will be held in the clinic area on 3B.

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 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.

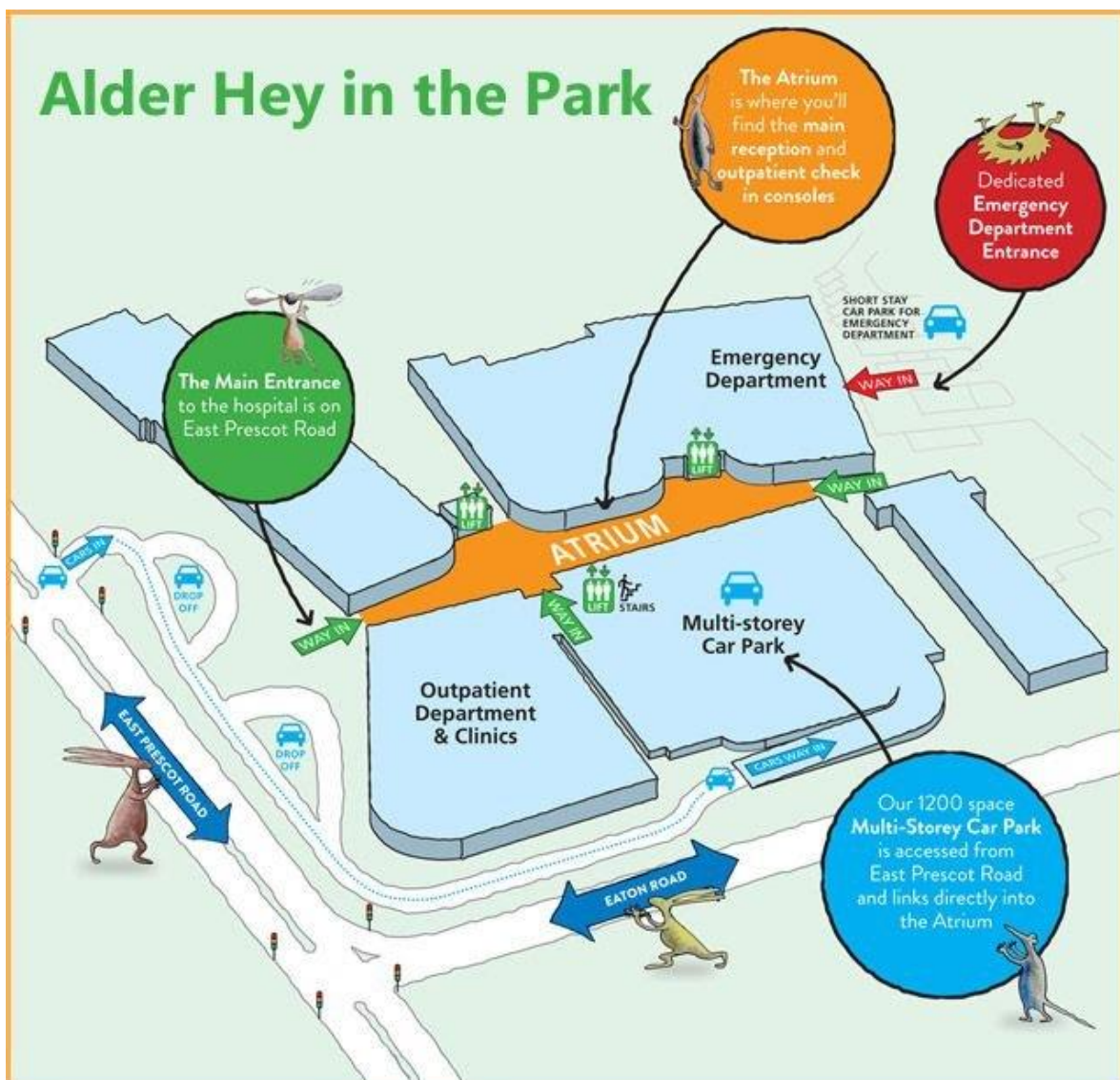
The drop in service is for

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



Where to go if your child is unwell

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



Out of hours

If you require urgent (but not medical emergency) advice out of hours, ring switchboard (0151 228 4811) who will put you through to nursing staff on ward 3B. They will speak to the Consultant Haematologist on call, and will get back to you with any advice or a plan. If your child is acutely unwell please attend your local emergency department. Please ensure that you take any prescribed medication with you.

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.

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.

When is clinic?

Monday am	IBD Clinic
Wednesday pm	Consultant led clinic



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 5070, as soon as you know that you cannot attend, so that the appointment can be rearranged. Or you can use the Alder Hey website.

How often does my child need to come to clinic?

Most children will be seen in clinic every 3/6 months or at least annually.

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 5070** 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?

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 2.1. Please report to reception staff to let them know that you are here (or again you can use the digital platform). Please arrive on time for your appointment.

Your child will be called for height and weight measurement 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.

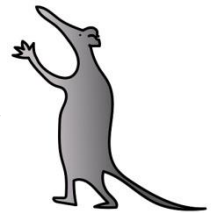
If required you may also visit the specialist physiotherapist in the physiotherapy department.

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 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.



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 ward daily and will keep up to date with your child's progress via the hospital systems. The hospital Meditech system will allow the specialist team to keep up to date with your child's progress.

Parents / carers and siblings can visit at any time. Other visitors can visit between 10 am to 7.00pm. All child visitors must be accompanied by a parent / carer.

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 Haemophilia and Inherited Bleeding Disorders Team offer?

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

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. 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

Every year we 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.

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, Eaton Road, Liverpool L12 2AP.

Further information

If you have any questions or want any further information, please contact your haemophilia and bleeding disorders team on 0151 252 5070.

Useful websites

www.alderhey.co.uk

www.haemophilia.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
Alder Hey
Eaton Road
Liverpool
L12 2AP

Tel: 0151 228 4811
www.alderhey.nhs.uk

