

Children's haematology

Vaccinations, medication and travel for children with thalassaemia and sickle cell disease

Information for patients, relatives and carers

Introduction

This leaflet will help answer some of the questions you may have about travel abroad. It is not meant to replace the consultation between you and the medical team, but aims to help you understand more about what you discussed together.

Medication

Certain medications for people with sickle cell disease and thalassaemia need to be given or monitored in hospital, and will be prescribed in clinic. These medications may include:

- Hydroxycarbamide
- Testosterone
- Desferrioxamine (Desferal®)
- Deferiprone (Ferriprox®)
- Deferasirox (Exjade®)

Other medications should be prescribed by your GP.

If your child has had their spleen removed, they should take a preventative dose of penicillin V (penicillin prophylaxis) twice a day for the rest of their life to reduce the risk of illness and death. This is available in a liquid and tablet form. The bottles of liquid expire after one week, so we encourage children to learn how to take tablets as soon as it is possible. If liquid is needed, we recommend that the repeat prescription be for eight to ten bottles. The pharmacist should dispense it as a powder and teach parents to make it up with the required amount of water.

Folic acid is a B vitamin that is important for making new cells. Patients with sickle cell disease may become deficient in folic acid. This is because their red blood cells can last less than a month, compared to three months in people without a haemoglobin disorder.

Vaccinations

The vaccinations listed below are recommended and you can get them at your GP surgery.

Some children may have missed the normal childhood vaccination schedule or may have been vaccinated abroad where the schedule may have been different. Please discuss this with your GP so that they can bring your child up to date with any vaccinations they may have missed.

The UK childhood vaccination schedule is:

- Hepatitis B vaccination
- Pneumococcal polysaccharide vaccine PPV23 (given every 5 years from age 2 years) against pneumococcus infections
- Haemophilus influenzae type B (Hib) vaccine
- Meningococcal ACWY vaccine
- Meningococcal B vaccine
- BCG
- Annual influenza (make appointment with your GP in the autumn or winter months every year)

Travel advice

Check if you need to get any travel vaccines for the country you are travelling to. Arrange these through your GP practice or a travel clinic at least six weeks in advance. If you are visiting an area that requires yellow fever vaccination and are currently taking the drug hydroxycarbamide please talk to your child's hospital specialist, as we might recommend you don't have it.

Before you travel

Travelling abroad can be stressful and could also lead to an increased risk of crises due to blood clots (thrombosis), infection, fatigue (extreme tiredness), dehydration and change of climate.

Discuss your travel plans with your GP or care team as early as possible (at least six weeks before you travel) so they can advise on any necessary precautions and confirm your child is well enough to undertake the trip.

When making the bookings, make sure the travel agent, airline and insurance company are all aware of your child's medical condition and that you will need to travel with prescribed medication. This might include antibiotics and any other medication.

Please take time to find out about the medical facilities available in the country you are visiting and know where the nearest treatment centre or hospital is. Your hospital specialist will be able to assist with this and the Sickle Cell Society keeps an up-to-date list of overseas sickle cell organisations.

If your child has developed a severe sickle cell crisis within two weeks of a planned visit abroad, you should not travel. If your child is unwell the day before or on the day you are due to travel, speak to your GP or hospital specialist team who will advise you whether it is safe for you to travel.

What to carry with you

A copy of a recent outpatient clinic letter or medical report from your consultant or other member of the hospital team that shows your child's diagnosis and treatment. This should include your child's usual haemoglobin level and medications, and who to contact for advice in an emergency.

For insurance purposes, you might need a letter to confirm that your child is medically fit to travel and, possibly, a recent blood test result. You should ask the insurance company about this.

You need to have your child's antibiotics and other medicines including any painkillers you might need to last the whole trip. It is best to arrange this at least two weeks before travel. Take a copy of any prescriptions with you too. For air travel, all medicines should be packed in your hand luggage.

Air travel

Keep your child mobile (walk around at least every half hour) and well-hydrated.

- Encourage your child to drink plenty of fluids, preferably water. You could purchase water bottles after going through security. Drinking it will keep them hydrated and help prevent dehydration and sickle cell crises.
- If your child is well and in a pressurised cabin, they will not need extra oxygen. If they need oxygen, you will have to tell the airline in advance. They will usually send you a form that your hospital specialist needs to complete. Some airlines charge for providing oxygen. Contact your airline as soon as possible about this.
- There is a possible increased risk of blood blockage in the spleen (splenic infarct) from air travel, and your doctor should check this if your child has pain in the left upper part of their abdomen.

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- They should wear appropriate flight socks to reduce the risk of blood clots (thrombosis). - You can buy these in most large pharmacy stores
 - Carry warm clothing or use a blanket to prevent your child getting cold. The temperature on the plane is often cold

Overland travel

Keep your child mobile, well-hydrated, and avoid them getting very tired (fatigue).

Antibiotics

- Your child should take their regular penicillin or equivalent (such as erythromycin) if they are allergic to penicillin.
- Ask your GP for a treatment course of antibiotics in case your child needs them. However, if your child is truly unwell when you are away, they will need to see a doctor.
- Get treatment straight away for dog bites and tick bites.
- Get treatment straight away for other infections. Remember that if your child has sickle cell disease, their spleen does not work well and therefore they are more prone to infections. This risk is reduced with vaccinations and penicillin, but it doesn't completely go away.

Malaria

Sickle cell and thalassaemia do not protect your child from malaria. Malaria in sickle cell can be life-threatening. You should make sure they take the relevant anti-malarial tablets prescribed to the country/area you are visiting. Do this even if they used to live in a malarial area or go there regularly. Your GP or travel clinic can advise on the choice of antimalarial medication.

If your child has G6PD deficiency, please ensure that you mention this when getting their anti-malarial medication, as some medications may cause problems in those with G6PD deficiency. Your child might need to start the medicine a little earlier than recommended to ensure that they are not having any side effects.

Diarrhoea

Diarrhoea is common among travelers abroad. If you have sickle cell disease this can cause dehydration, which can trigger a crisis. To avoid this, we recommend carrying a supply of oral rehydration salt sachets. You can buy these from your local pharmacy. If your child develops a fever or you notice blood in their poo, you should get immediate medical advice.

Other infections

If you are trekking or camping you may be at risk of a rare infection called babesiosis carried by ticks. Cover exposed skin, for example, by wearing long trousers, to reduce the risk of any infections transmitted by ticks.

Get treatment urgently for any bites (especially dog) as these can lead to serious infections. You need to keep any bites clean and get medical advice if there are any signs of fever or infection.

Ensure you use insect repellent containing DEET, wear protective clothing and use mosquito nets.

Access to healthcare abroad and travel insurance

Insurance

Get travel insurance that covers costs for bringing you and your child back to the UK if they become ill. You need to tell the insurance company about their thalassaemia or sickle cell disease or their insurance will be invalid. The Sickle Cell Society may be able to recommend insurers.

Application form available from post office

It is strongly advised that you take out travel insurance that covers medical costs. The UK Global Health Insurance Card (GHIC) does not cover all costs such as the cost of coming back to the UK for treatment, any private treatment (not all hospitals or doctors provide state-funded care) or any non-emergency treatment. The GHIC does not cover you for travel to any country outside the EEA so make sure you have taken out adequate insurance if you travel outside the European Economic Area (EEA). Read the policy details carefully to be sure you are covered for any eventuality, such as last minute cancellation due to illness and travelling back to the UK by air ambulance. An up-to-date medical report may be needed so plan some weeks in advance if possible.

A UK GHIC is free and lasts up to 5 years. Apply for your card on the NHS website and avoid unofficial sites, as they may charge a fee.

For further information see NHS Splenectomy Information for Patients:

www.gov.uk/government/publications/splenectomy-leaflet-and-card

Guidance on access to healthcare abroad can be found at: www.nhs.uk/using-the-nhs/healthcare-abroad/

If you are travelling to a country within the European Economic Area (EEA) you are entitled to emergency healthcare at a reduced cost or free. To access this, you need to get a European

Health Insurance Card (EHIC) which is free of charge prior to travel. This can be requested on: www.nhs.uk/NHSEngland/Healthcareabroad/EHIC

Contact details

- **Haemoglobinopathies admin team:** 0203 312 6157
- **Haemoglobinopathies clinical nurse specialist team (09.00 to 17.00):** 07795651153, imperial.paediatrichaemoglobinopathies@nhs.net
- **Paediatric haematology day unit (PHDU):** 0203 312 5080/5081
- **Paediatric site practitioner:** 07824625419

The team

- Dr Kirstin Lund, consultant paediatric haematologist,
- Professor Josu de la Fuente, consultant paediatric haematologist
- Dr Adam Gassas, consultant paediatric haematologist
- Dr Toni Petterson, consultant paediatric haematologist
- Dr Leena Karnik, consultant paediatric haematologist
- Miss Catherine Mkandawire, matron (Haemoglobinopathies and apheresis children and young people)
- Miss Kajal Rai, clinical nurse specialist (Haemoglobinopathies children and young people)
- Ms Nancy Huntley, clinical nurse specialist (Apheresis children and young people)
- Miss Ristell Fernandes, clinical nurse specialist (Apheresis children and young people)
- Mr Renzo Tiong, clinical nurse specialist (Apheresis children and young people)

Further information

<https://www.imperial.nhs.uk/our-services/adolescent-and-young-adult-healthcare---11to25>

<https://www.readysteadygo.net/>

Sickle Cell Society

020 8861 7795

sicklecellsociety.org

UK Thalassaemia Society

020 8882 0011

office@ukts.org

ukts.org

Sickle Cell and Young Stroke Survivors (SCYSS)

0800 084 2809 or 0207 277 2777

info@scyss.org

scyss.org

Contact

The charity for families with disabled children

<https://contact.org.uk/>

Family Fund

<https://www.familyfund.org.uk/>

Grants are available for families raising a child or young person with a long-term disability, disabling condition or life-limiting illness, and living on a low income.

The Hope Project Scotland

07756 266691

thehopeprojectscotland.org.uk

Citizens Advice Bureau

<https://www.citizensadvice.org.uk/>

The Care Information Exchange (CIE)

CIE gives secure online access to information from the hospital such as test results, appointments and letters. Young people and their parents can also add things like symptoms the young person is experiencing to give a more complete record. To register and access the record QR code below to download the application.

Everyone registering will need to complete a form, show proof of identification, and have an email address. The email address will be the login name, and the address for notifications when something new is added to the record. Go to www.careinformationexchange-nwl.nhs.uk/ or scan this QR code with your phone camera to find out more and register:



How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk