PHSE/Citizenship in Secondary Schools

Anyone can be a carrier of thalassaemia although It is more common in people from the following backgrounds – Mediterranean, Pakistani, Indian, Bangladeshi, Middle Eastern, South East Asian and Eastern European. It is therefore very important to raise awareness of the condition among these communities. Carriers are symptom-free and usually unaware that they carry the condition. A simple blood test can determine whether or not a person is a carrier. If you would like information leaflets for your students please contact the UK Thalassaemia Society. It may also be possible to arrange school visits to assist your students in learning about thalassaemia and the importance of screening. Please contact the Society for further information.

Acknowledgement

The UK Thalassaemia Society thanks the following for their advice:

- Isabel Adams, *Thalassaemia Nurse Specialist, Birmingham Children's Hospital (BCH)*
- Munira Bharwani, *parent*
- Dr Philip J Darbyshire, *Consultant Paediatric Haematologist, BCH*
- Jane Carrington-Porter, *teacher, of James Brindley School based at BCH*
- Susan Crawford, *Specialist Nurse Haemoglobinopathy, B'ham Sickle Cell/ Thalassaemia Services*
- Pamela Hayes, *School Nurse, Swanshurst School, Birmingham*
- Nazam Rehman, *parent*

The UK Thalassaemia Society thanks Jeans for Genes for funding this project

Helping children with genetic disorders

Useful Contacts

UK Thalassaemia Society
19 The Broadway, Southgate Circus, London N14 6PH
Tel 020 8882 0011 • Fax 020 8882 8618
Email office@ukts.org • www.ukts.org
Registered Charity No. 275107

NHS Sickle Cell and Thalassaemia Screening Programme

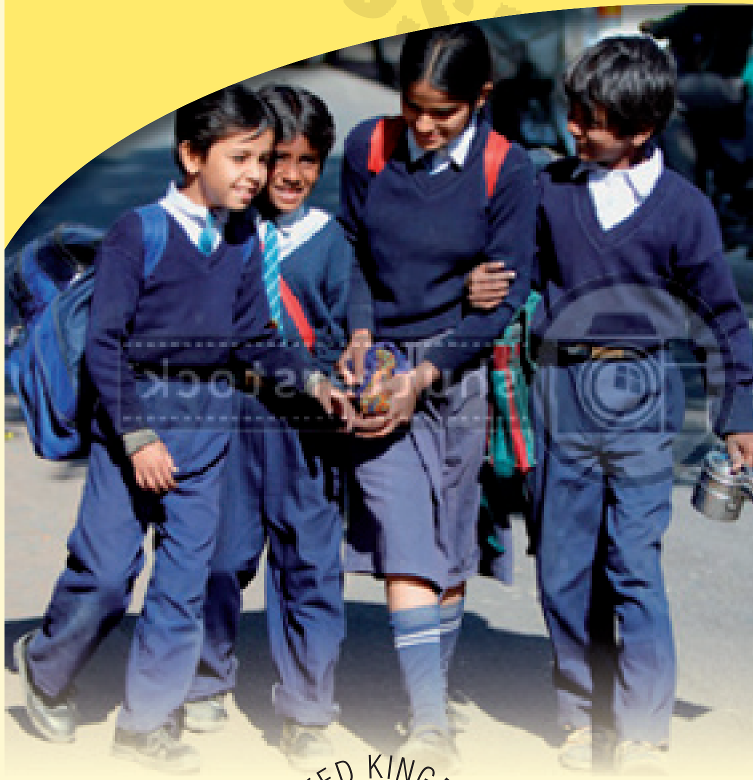
Division of Health and Social Care Research
King's College London School of Medicine, 7th Floor, Capitol House
42 Weston Street, London SE1 3QD
Tel 020 7848 6634 • Fax 020 7848 662
Email haemscreening@kcl.ac.uk
www.screening.nhs.uk/sickleandthal

Important Information

Child's Name	
Class/Year	
Address	
Names and emergency contact numbers for Parents/Guardians	
Hospital Contact Details	
Haematology Consultant Name/ Number	
Haematology Nurse Specialist Name/Number	
Any other important contact details	

If you teach a child who has Thalassaemia

– You need to read this leaflet



Thalassaemia is a genetically inherited anaemia

It is a lifelong condition.

Some people are healthy (symptom free) carriers of the condition.

If a mother and father are BOTH carriers, they risk passing on the condition to some of their children.

A child who has thalassaemia will receive regular blood transfusions, typically every 4 weeks (this may vary). He or she will also be on constant medication.

As with any long term medical condition, it is essential to maintain frequent, open communication with the child's parent/guardian(s) about the child's treatment.

A child with thalassaemia is a normal child and should be treated exactly as other children in terms of their education and expectations.

What you need to know

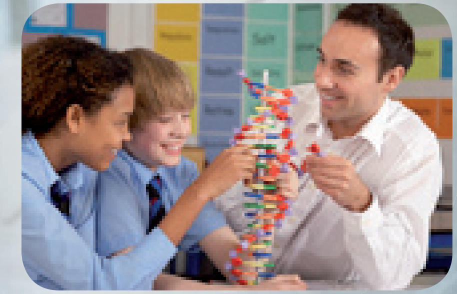
- Children with thalassaemia may tire easily in the week before transfusion.
- They may be receiving daily medication by injection. The injection sites can be sore, itchy and may appear bruised.
- They may have a permanent intravenous injection site (vascuport/portacath) fitted under the skin. If so, they should not participate in contact sports. If the vascuport is in use swimming must be avoided. Please check with the parents/guardians about this.
- Thalassaemia is not a bleeding disorder (i.e. normal physical contact will not cause bleeding as may happen in some conditions, e.g. haemophilia).
- Medication may discolour the urine or stools.
- No special diet is required.
- There is no reason why the child should be excluded from school trips unless the medical team have advised against it. If in doubt ask for a letter from the child's doctor or nurse specialist.
- A child with thalassaemia will have frequent hospital appointments which can affect their record of attendance. PLEASE NOTE that they can be awarded "medical" register points for necessary regular hospital visits (e.g. for transfusion). Consult your local education authority for further advice.
- All long term conditions have psychosocial implications for the child and his/her family. In particular, in some cases thalassaemia may cause problems with growth and development. This can cause problems with peer comparison and be very distressing to the adolescent child with thalassaemia. Please bear this in mind when dealing with any social or behavioural difficulties and consult the parents/guardians if you have any concerns.

The following symptoms should **ALWAYS** be taken seriously and reported immediately to the child's parents/guardians and/or the child's medical team:-

- **Fever and/or flu-like symptoms**
- **Abdominal pain**

Note to P.E. Teachers

Children with thalassaemia should be encouraged to take part in normal exercise as it can be beneficial to them. However, you should bear in mind the points under "What you need to know". DO NOT REFUSE if the child asks to be excused from or stop any activity due to fatigue or pain.



Note to Science Teachers

You can obtain further information on thalassaemia for use in lessons on genetics etc from the UK Thalassaemia Society.