******

Haematology Department

**Sickle Cell Disease – Chronic Complications**

**Retinopathy**

Information for parents and carers

**Introduction**

This leaflet is designed to explain about the long term (chronic) complications of sickle cell disease. The information does not cover everything. If you are ever worried about your child then please contact your Sickle Cell Team or take your child to Accident and Emergency Department.

**What is retinopathy?**

Retinopathy is damage to the back of the eye. The retina is the part of the eye that you see with, it processes the light coming into the eye and sends signals to the brain

**What causes retinopathy in sickle cell disease?**

Sickle red blood cells get trapped in the small blood vessels of the retina. This can cause damage to the retina as there is a decreased blood flow. It can also cause bleeding in the eye. When blood vessels are blocked, the eye makes new thinner vessels to replace the blocked vessels. These may break open and bleed. The bleeding causes damage to the retina and can also cause the retina to become loose from the rest of the eye. This is known as a detached retina.

**How common is retinopathy in sickle cell disease?**

Sickle cell retinopathy is more common in children with sickle cell disease. Approximately one third of individuals with sickle cell disease will get retinopathy.

**Does retinopathy occur in both eyes?**

Retinopathy can occur in one eye or both eyes.

**What are the symptoms of retinopathy?**

In the early stages of retinopathy there may be no symptoms. As it gets worse the symptoms of retinopathy can include:

* Coloured spots, flashes or dark shadows that ‘float’ in your field of vision – floaters.
* ****Blurred vision.
* Vision blocked by patches or streaks.
* Reduced night vision.
* Most seriously, sudden vision loss.

**What should I do if my child has problems with their vision?**

If your child has sudden changes in their vision you should get them reviewed by a doctor straight away. Take them to the Accident and Emergency Department. Changes in vision can also be a symptom of stroke.

If the changes in vision are more gradual then you should report them to your Sickle Cell Team. They may suggest that you take them to your local optician for an eye test or they will refer you to the opthalmologist (eye doctor) at the hospital. They will perform an eye test to check the blood vessels in the back of the eye. This will usually involve putting in eye drops so the doctor can see the back of the eye more easily.

**Can retinopathy cause my child to go blind?**

Retinopathy usually causes vision changes but in rare cases it can cause blindness. Therefore if you notice any changes in your child's vision, report them to your sickle cell team.

**What is the treatment for retinopathy?**

In mild cases of retinopathy your child will be followed up regularly by the opthalmologist. More severe retinopathy can be treated by laser treatment but sometimes surgery may be necessary.

**How can retinopathy be prevented?**

From the age of 10 years your child will have an eye test every year. This will help to pick up any early signs of retinopathy.

**Further information**

If you have any questions or want any further information please contact your Sickle Cell Team on 0151 252 5070.

**Useful websites**

[www.alderhey.co.uk](http://www.alderhey.co.uk)

[www.sicklecellsociety.co.uk](http://www.sicklecellsociety.co.uk)

Alder Hey Children's NHS Foundation Trust is neither liable for the contents of any external internet site listed, nor does it endorse any commercial product or service mentioned or advised on any of the sites.

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 leaflet 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](http://www.alderhey.nhs.uk)

**© Alder Hey Review Date: April 2024 PIAG: 0050**