

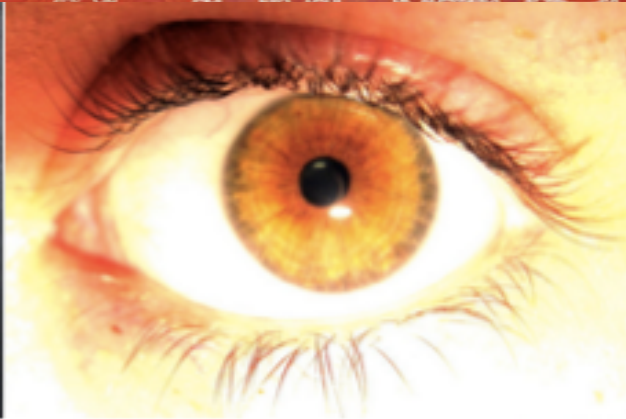
HEREDITARY SPHEROCYTOSIS

Information for patients and parents



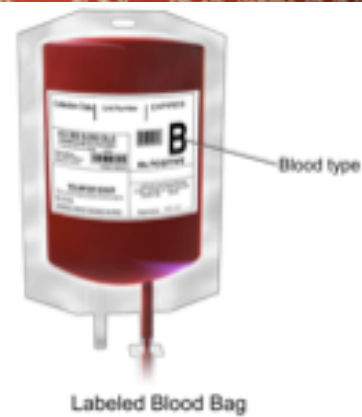
WHAT IS IT?

Hereditary Spherocytosis (HS) is an inherited condition of red blood cells. Due to an inborn 'error' in the code of genes that make the surface of red blood cells, these become fragile and get destroyed too quickly. Instead of surviving 3 months, they survive only a few weeks.



WHAT ARE THE SYMPTOMS?

The main symptom is anaemia (not enough red blood cells) and patients feel tired and weak, without energy. They may look pale. They can have jaundice- the whites of their eyes become yellow. This is not harmful, but shows that the blood cells are being destroyed too quickly.



WILL I NEED A BLOOD TRANSFUSION ?

Most patients are well most of the time, but may become weaker if they get a heavy cold or infection. Some patients may then need a transfusion.

WHAT ARE THE COMPLICATIONS?

- Having HS does not mean giving up on living a full and active life. Some complications may occur, but they each have solutions:
- Gallstones: these occur from the increased breakdown in red blood cells. The gallbladder may need to be removed in a minor operation
- Occasional severe anaemia: this may require occasional transfusions
- Persistent severe anaemia: this may require an operation to remove the spleen, usually a keyhole procedure.





LOOKING AFTER YOURSELF

Plenty of people want to know- is there anything I can do to help myself/my child be as well as possible with HS? It would be nice if there was a straightforward answer, a simple change in diet for example.

While there isn't any one thing that will make all the difference, keeping well and healthy will help in the long term. This includes a good diet and regular exercise, as well as staying on top of any medications prescribed:

1. Folic acid: this is a crucial vitamin for patients with fragile red blood cells and should be taken every day.
2. Patients who have had their spleen removed should be on daily preventative antibiotics and regular vaccines to prevent severe infections.

CAN WE HELP?

CAN (congenital anaemia network) is a charity specifically for patients with inherited anaemias. It was started by a group of patients and doctors, working together to tackle some of the problems of having an inherited anaemia- the lack of information and the loneliness of not knowing anyone else with your condition.

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Getting the opportunity to meet other patients with the same condition as me has been really helpful in finding better ways of keeping well.

We run events for patients to meet each other, as well as provide some additional support and services for patients who need that extra bit of help. We also want to help give patients more accurate information about their conditions. If you want to know more visit www.togetherwecan.uk or email us on info@togetherwecan.uk



**CONGENITAL
ANAEMIA
NETWORK**