

dbas^{UK}

THE UK'S DIAMOND BLACKFAN
ANAEMIA SYNDROME CHARITY

An Introduction What is DBAS?



This literature has been designed by **DBAS UK** with kind support and guidance from the **Aplastic Anaemia Trust**. Check out www.theaat.org.uk/marrowkidz for further information.



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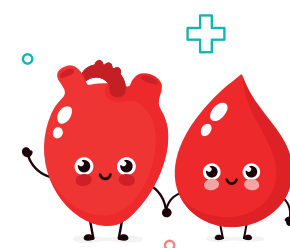
DBAS UK Registered Charity 1083179

What is DBAS

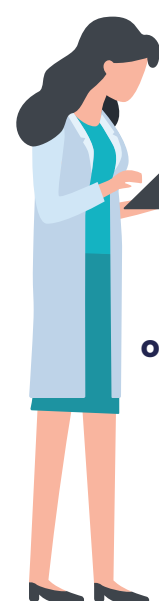
Diamond Blackfan Anaemia Syndrome (DBAS) is a rare blood condition where the bone marrow fails to produce enough red blood cells.

Bone marrow and blood cells

Your blood is mostly made up of four things: red blood cells, white blood cells, other cells called platelets and a liquid called plasma, which the blood cells and platelets move in.



Bone marrow is the spongy part inside your big bones. It is a bit like a cell-making factory where new blood cells are made. When they are first made by the bone marrow they are called stem cells. These stem cells grow into red blood cells, white blood cells and platelets. Red blood cells carry oxygen around your body. They are the reason your blood is red. These red blood cells are necessary for life since they carry oxygen around the body.



Red blood cells carry oxygen around the body

What will make me better?

AS YET THERE IS no cure but DBAS is very treatable with help from hospitals.

Many people with DBAS are treated with blood transfusions, often monthly.

Some DBAS People can respond to a high dose of steroids, often taken every other day

For some children (but not everyone), your bone marrow might need to be replaced by healthy bone marrow, which has been donated by a different kind person. For this to work well, the donated bone marrow has to be a good match with your own body.

On rare occasions it has been known for DBAS patients to go into remission, with a temporary or permanent cessation of symptoms.

Talking to somebody. We know that having DBAS can be difficult. If you have any questions or worries, please talk to somebody about this. Your family, your brother, your sister, your friends and your doctors are all here to help you as much as they can.



Why is this happening?

Diamond Blackfan anaemia is a genetic syndrome and is caused changes (mutations) in ribosomal protein genes in about 80-85% of those affected.

DBAS is a rare syndrome. It is a genetic syndrome caused by changes in the genes (mutations).

What signs will I notice?

Let's look at some of the things that might be happening.

Feeling tired - Without enough red blood cells, you might feel tired or out of breath and look pale. DBAS can cause fatigue, poor growth, lack of appetite and a pale complexion. In about a half of cases patients also suffer associated congenital abnormalities.

Other Problems - Some affected children are short for their age and may have delayed puberty.



What DBAS UK can do...

DBAS UK is a registered charity (1083179) run by volunteers. We offer support, research and hope to the DBAS community by bringing families together to share their experiences, communicate the latest medical information and raise funds to support those with DBAS in the UK.

Telephone support line UK Family & Patient Support Line **0845 094 1548** will provide invaluable support to patients and their families at a difficult and confusing time.

We also hold an annual conference for all DBAS families in the UK.

www.diamondblackfan.org.uk