

Dear Clinician,

Our Charity is focused on supporting families with a suspected or clinical diagnosis of Diamond Blackfan Anaemia.

When families are diagnosed with this condition it is understandably a very difficult time for them and they often ask for support from the Charity to act as their advocate. A common question from families is how they can obtain a second opinion. This is particularly helpful in the context of the lack of general awareness of this extremely rare syndrome, which leaves parents in a position of trying to obtain as much information as possible from as many sources as available.

We as a Charity do not want to obstruct treatment or diagnosis, but want to support the patient and their family to obtain a second opinion if they so wish. In some cases, families will already have a clinical team in mind, while in others they will rely on you to suggest another centre for second opinion. We really appreciate your support in this process.

We aim to support all families in obtaining a care package which works smoothly irrespective of their local hospital and tertiary centre. We are grateful to you for providing support in working with other professionals for the benefit of our patients.

We endorse and promote the internationally ratified care pathway for the management of DBA. If you would require any further assistance please do not hesitate to contact the Charity Chair for further information.

Yours sincerely,

Leisa Batkin
DBAUK Chair

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