

Haemoglobinopathy



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Patients' view on new Social Services booklet – to be launched July 7th 2004

Views from patients living with Sickle Cell or Thalassaemia.

Mabel Alli met with patients at Hammersmith Hospital to discuss how a booklet full of information on social services would benefit them most. She asked the questions:

Does the booklet provide the right information?

Is there too much / too little text?

Is it easy to read?

Is the information laid out correctly?

Is the booklet a quality product that patients would want to read?

All the comments received from that day were taken back and implemented into the final draft, the booklet will be out soon and hope it meets the expectations of all those involved. Mabel would like to thank all of those involved in making this possible, with a special mention to Elaine Beresford the senior social worker who arranged the day.



Elaine Beresford with patients on the day.

“It’s a new beginning, this booklet is useful, and straight to the point”

See overleaf for other comments made on the booklet.

Visit our website on www.haemoglobinopathy.org

What patients said about the new booklet - to be launched July 7th 2004:

“This booklet is useful for even carers or friends of patients to have”

“Things like this are easy to read even for people with traits”

“Who is sponsoring the booklet ?”

“It’s about time- thanks”

Other comments from the day were noted, namely lack of information on things to do in an emergency or help in crisis situation, and information on the haemoglobinopathy register, more information on how to get an initial assessment from social services.

These points are valid ones and we have gone back and added them to the booklet in order to make it more useful for those for whom this booklet was intended. Obviously not all points could be added due to sheer volume, however this booklet will be re-assessed in six months time. So if you see the booklet and have comments on it please contact us on 020 8795 6780.

