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Dear Colleague

I write to update you all, on what has been a very busy year for the Forum and I think a year that has seen genuine progress in many aspects of Haemoglobinopathy issues.

Firstly as you know the **screening programme** goes from strength to strength, neonatal screening now established across England and Antenatal screening being rolled out. Educational resources relating to this programme have been provided by the Pegasus initiative. The screening programme has also taken on the brief of clinical service development following the rather belated realisation by the Department of Health that there were not the organised clinical services available to cope with the numbers being detected by the screening programme. I think we must acknowledge the lead Alison Streetly has given in getting this agenda moved forward.

Several initiatives are now moving in the **clinical arena**. There were standards of care drawn up for both Thalassaemia (adults and children) and Sickle cell disease (children, adults in progress) and these have been endorsed by the Department of Health. The clinical networks outlined in the standards I think now are seen to officially exist, certainly as far as children are concerned the next step is to try and identify what resources are needed to allow the networks to achieve the required standards. The DH has earmarked money for training medical, nursing and scientific staff and some of this money has had to be used quickly in order not to lose it in this financial year. I am aware as are others that a transparent and fair process needs to be set up for the acquisition of any available training resources in future years.

The DH has also endorsed an **external peer review programme** of the new clinical networks. I hope to post on the website the final draft of a series of quality standards which myself, Anne Yardumian and Jane Eminson (West Midlands Cancer peer review team) have written, these are a distillation of standards documents, we would be interested in any comments. The purpose of these peer review visits is very much a learning process as I don't think any unit will be able to fulfill the requirements at present. The intention is that a report is produced which will inform both the host Trust, commissioners, staff and patients about the present level of service and identify areas where either organisational change, resources or both are needed to bring the service up to that needed. I am sure many of you are already familiar with this type of approach. Anyone interested in joining appraisal teams please contact either myself or Anne.

The DH had I think acknowledged that we do not have at present even the most basic data about numbers, it is recognised that in the long term data must be collected but as an urgent interim measure has asked a group in Manchester who already run a Haemophilia **database** to coordinate collection of basic data on numbers, they are very concerned about the risk of new variant CJD and the fact we do not even really know the numbers on long term transfusion. This is vital in assessing the resources that may be need in years to come and I hope you will all facilitate this process. It does not mean that any long term database will be sited in Manchester. I know many groups have an interest in this area and any development must again be an open process.

There is going to be a **stakeholder meeting** in November this year to address many of the issues and the questions arising from these quite rapid developments. It is vital all involved in Haemoglobinopathy have input to these developments.

I hope some of you will have seen the new revised website hosted by the UK Thakassaemia society. A big thanks to the society and Mike Michael in particular for this. You will already find on there some interim guidelines on chelation and the intention is to put on other information including the quality standards as such documents become available. Any comments on what you would like to see on the site gratefully received, to any committee member or Mike himself.

I am aware that **funding for new developments** is very difficult. The difficulties we are having in getting Exjade funded and the establishment of Trans cranial Doppler services being two obvious examples. I think a critical area here is the way Haemoglobinopathy services are funded. We with others are trying to make the case to commissioners that at least some aspects of services for Haemoglobin disorders should be funded in a different way possibly via the SSA route, the present arrangements are not appropriate for these managed networks. I would ask you to pass on the quality standards to your own commissioners and ask them how you might work with them to achieve them. We are also working to try and ensure that the new tariff prices accurately reflect the costs of running services, if they do not it will be a major disincentive to Trusts who are involved in this area.

Turning briefly to meetings, I hope those of you who went to Bournemouth felt the red cell sessions worthwhile, the feedback was positive and it might perhaps be repeated in 2-3 years time. We do now have an official link with the British Society for Haematology. The next academic meeting is in Sheffield on 22/11/07 and the training course at St Thomas's run by Dr Baba Inusa is in early October. We hope the Liverpool course will run next year. Again any comments on meetings, contents or any other matters gratefully received. It is a bit of a juggling act trying to keep most of the people happy most of the time but we do try!

We hope to establish a red cell fellowship for a scientist in conjunction with BSH, Sickle cell society and Thalassaemia society late in the year. We continue to work closely with Micheal Micheal, Asa'ah Nkohkwo and their colleagues in a variety of arenas to promote Haemoglobinopathy issues. Dr Jo Howard is leading a group who are putting in an application to the HTA. The HTA are asking for research proposals in aspects of Sickle pain, there are some very exciting proposals which are actually trying to bring in some science to an area where new initiatives are needed. Please contact Jo for more information.

The NCEPOD mortality study is now almost complete and will shortly be analysed. The study has been successful in that they do seem to have been able to evaluate a number a deaths. It is hoped that the results of the study will be presented at the spring Academic meeting next year. Thank you all for your support of this important audit .

Finally the new membership details are on the website, please do encourage new members to join, it is an exciting time to be involved in this area I think the Forum is rightly taking on new roles and a strong and involved membership will help to move things forward .

Please do contact either myself or other committee members if you have comments or concerns about Forum activities.

Best wishes

Dr Phil J Derbyshire
on behalf of Forum Committee

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