UK Forum on Haemoglobin Disorders

Purpose Statment

The UK Forum on Haemoglobin Disorders is a multi-disciplinary group of health care professionals interested in all aspects of sickle cell disease, thalassaemia and related conditions.

It started informally in London as a group of colleagues, meeting to discuss cases and clinical management challenges, but in the early '90's benefited from becoming a national organisation, with much wider membership and more formal status.

The Forum has about 100 'paid-up' members and - up to 400 who attend the twice yearly scientific meetings. It is now a recognised and respected organization, involved in formulating national policy for screening and management of these conditions. The expansion of the Forum has mirrored the growing awareness of haemoglobinopathies as an increasingly prevalent group of disorders with impact across all ethnic groups.

These disorders represent a major challenge to the broader health community particularly in inner city areas.

Membership includes specialist and interested nurses and counsellors, biomedical scientists, psychologists, paediatricians, haematologists and paediatric haematologists. Patients are represented by standing committee members from the two major voluntary organisations (Sickle Cell Society and UK Thalassaemia Society).

The Forum has strong links with other professional groups and aspires, by virtue of its broad based membership, to be able to give a balanced and informed view of most aspects of the haemoglobin disorders.

Scope

The Forum aims to:

- Provide a focus for interested professionals to meet and address issues of mutual interest for them and their patients.
- Work jointly with other organisations such as the British Society of Haematology, the Medical Colleges, National Screening committee and others to increase recognition of haemoglobin disorders as a key sub-specialty area.

- Enhance the recognition of these conditions in the broader health care community emphasizing the important ethnic and cultural aspects of these disorders.

- Hold twice yearly scientific and educational meetings which usually include renowned international speakers for key updates, case presentations and discussion of new research developments and key clinical management issues. One meeting per year is in London and one in the Midlands or North of England.

- Input to other educational meetings for training or established health professionals.

- Work together with the main patient voluntary organisations to optimise care for people with sickle cell disease and thalassaemia across the UK.

- Address and influence the content of nursing, medical and biomedical scientist education in regard to these conditions.

- Work towards formal networks of care for people with these conditions, identifying specialist Centres with specific responsibilities.

- Support the development of national standards for screening, testing, and clinical care of people with haemoglobin disorders.

- Promote and supervise, with other agencies, the establishment of a peer review process, whereby specialist hospitals, local hospital centres and community services are visited and assessed, aiming to improve care by monitoring adherence to recommended standards.

- Share ideas and broaden study recruitment for relevant research studies.

- To provide a resource for those commissioning hospital and community services for haemoglobin disorders.