

# Haemoglobinopathy News

## Like father like son

### A young person explains about sickle cell



Picture of Robert Ojeer addressing delegates at the 2006 network study day, following in his father's footsteps. His father, Mr Patrick Ojeer first addressed delegates at the annual study day in 2002 when Robert was only a child.

## Our health our say: Network study day 2006

Patients & carers during the group - work on sickle cell care explained that there are not enough clinical psychologists for better quality of life & confidence during the transition from childhood into adolescence. They called on health planners to listen to *children* sometimes.

This issue of the newsletter has been produced with funding from Novartis. To make any comments please Email: [communications@brentpct.nhs.uk](mailto:communications@brentpct.nhs.uk) or contact Dr Mabel Alli Tel: 020 8795 6749

## Better outcomes of care: the role of a specialist social worker



- delegates at the 2006 network study day have asked the network to sell the idea of a specialist social worker to other PCTs in the sector
- In a letter which was sent to the London Borough Hammersmith & Fulham (LBHF) and copied to the network coordinator, the Ealing & Hammersmith Patient Support Group gave examples of the kinds of benefit that patients receive from a specialist social worker
- The patient support group was writing to the LBHF when it came to their attention that they may lose the post of the Haemoglobinopathy Specialist Social Worker occupied by Elaine Beresford. This is the only specialist social worker post in the whole of NW London sector.
- The Patient Support Group said they wanted to be honest about the impact that the loss of Elaine's post will have on their lives. It will have great impact on the level of service that patients will receive, causing a lot of distress in the community and other members of staff

**Henry McCauley Sickle Cell Sufferer (HB SS)** writes: "Elaine has been always there for me and my sister who is also a sickle cell sufferer. She has supported me and has been a tower of strength to my family. She acted on my behalf when I had my housing problems. Without her I just do not know what I would do. It would be a disaster if her post was lost". End of quote



Picture of Sharon Mensah, specialist nurse Ealing PCT and the Patient Support Group

**Network Board  
meetings in 2007:**  
6<sup>th</sup> March  
4<sup>th</sup> June  
10<sup>th</sup> September  
10<sup>th</sup> December



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Picture of health workers planning services with patients & carers during study day group-work 2006

### **Helping NW London to performance monitor standards in haemoglobinopathy care**

The 2007 network annual study day will be held on Wednesday July 4<sup>th</sup> to explore the databases available for monitoring care standards e.g. hand-held patient records, GP notes, hospital notes etc. For a copy of the Performance Monitoring Forms for thalassaemia and/or sickle cell care, please contact: [carol.vanachter@brentpct.nhs.uk](mailto:carol.vanachter@brentpct.nhs.uk) or Tel: 0208 795 6735

## **BENEFITS OF A SPECIALIST SOCIAL WORKER**

Below are extracts from the letter to London Borough Hammersmith & Fulham (LBHF) from the Patient Support Group

**Extract one:**

WHY ARE WE LOOKING AT LOOSING SUCH A UNIQUE SERVICE?

WHY ARE THE OTHER CHRONIC DISEASES TRYING TO CREATE SPECIALIST POSTS WHILST WE ARE TRYING TO LOOSE THE ONE FOR SICKLE CELL & THALASSAEMIA WHICH IS THE COMMONEST GENETIC ILLNESS IN THE UK AND A CHRONIC LONG-TERM CONDITION?

WHAT WILL HAPPEN TO OUR CLIENT GROUP IF WE LOOSE THIS SOCIAL WORKER POST?

HOW CAN OUR CLIENTS SPECIALIST NEEDS BE MET ONCE WE LOOSE THIS POST?

*Signed Dolores Williams, chairperson Ealing Hammersmith & Fulham support group*

**Extract Two:**

I was turned down for my Disability Allowance and Elaine supported me with an appeal and I was successful. She seems to know with her knowledge and expertise what is so right, and how my illness can and cannot affect me,

*Paul Imbango Sickle Cell Sufferer*



Picture of Sickle Cell Society representative, Vincent Cox With a group-work facilitator at network study day 2006.



