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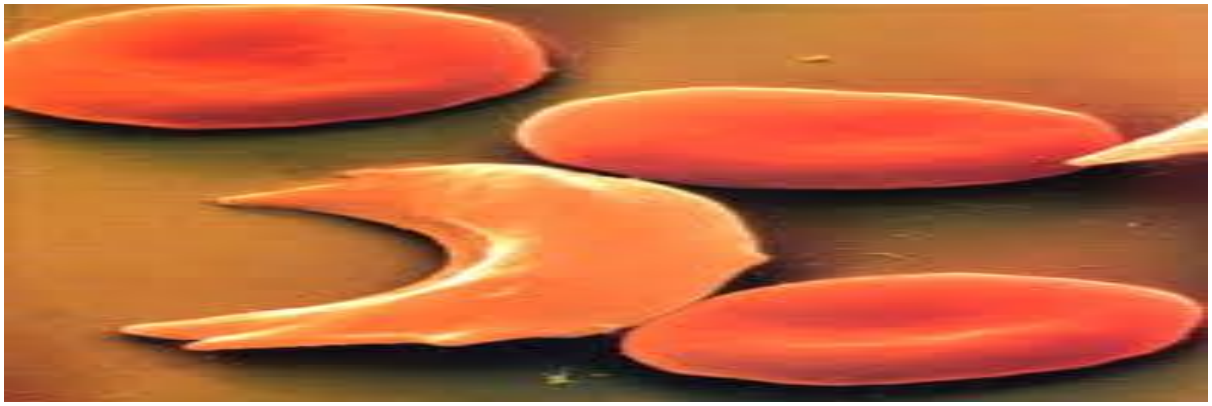
AfroSickle: *Network News*
To Promote Science and Improve Patient Care for SCD in Africa



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Network News: Headlines

- Doris Duke HU Trial – Ibadan
- Labs in Kumasi for Hemolysis and Vasculopathy.
- Pilot Studies
- New Participants in AfroSickleNet
- Topic for Discussion

Network News: The Stories

Doris Duke HU Trial – Ibadan:

Drs. Tayo and Hsu are in Ibadan this week working with Dr. Akingbola on issues related to randomization and treatment. Most the data are in hand to choose the high risk sub-set for the cohort that has been enrolled. In the next phase they will be assigned to low fixed dose HU in a cross-over design. More on this next month when Bamidele returns from Nigeria .

Lab for Studies on Hemolysis and Vasculopathy being organized in Kumasi:

Solomon has most of his equipment on site in KCCR in Kumasi and is in the process of hiring a physician and other staff.

Pilot Studies:

Hemolysis: A set of 20 samples from Ibadan has been shipped from Loyola to Pittsburgh for analysis of free heme and other measures of hemolysis. Next we hope to obtain samples from Yaounde, and if the data quality is adequate we will proceed to a study of 100 SS patients and 100 controls from each site. We do not yet have stored samples of SS patients from

Kumasi, although population controls are available. These studies are to demonstrate cooperation and feasibility across sites.

Common data set: We have agreed to use RedCap at all sites and over the next couple of months will try to organize a database that can allow pooling and comparison of clinical data across sites.

Use of Genetic Database Assembled through MalariaGen: Richard C. and Neil H. had a conference call with the Oxford group and in principle reached an agreement to allow us access to some of the GWAS data that might be of interest in an examination of haplotype diversity at the S locus and other genomics questions in sickle cell. The work plan has not yet been formulated, however, so it is not clear when this would start.

New Participants in AfroSickleNet:

Stephen Obaro, a pediatric infectious disease specialist, has agreed to participate in this network. He and Richard C. had several long conversations about options for research on infection and SCD. Stephen has just finished establishing a research platform in Igbo-Ora – near Ibadan – that will make it possible to identify children under the age of 5 with severe infection and evaluate the presence of variant hemoglobin using HPLC. This field setting could be extremely valuable for population-based studies of the burden of infection associated with SCD, and the trends in genotype by age – as a proxy measure of survival. The Loyola group has extensive DNA samples on families and adults in Igbora and could define

the genotype frequency of hemoglobin variants and modifying genes after age 21. Stephen will be visiting Loyola on Sept 7-8 to discuss the potential for collaboration.

Charmaine Royal, an investigator at the Duke Institute for Genome Sciences has a long-standing research interest in both the genetics and ELSI issues related to SCD. She has agreed to participate with us (more from Charmaine next month).

Topic for Discussion

Pursuant to the last discussion on the importance of advancing patient care and community involvement, this month's discussion theme (developed by Project Coordinator, Helen Nde) seeks to explore different means by which both goals can be achieved. See the accompanying document.

R. Cooper