

AfroSickle: Network News

To Promote Science and Improve Patient Care for SCD in Africa



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Welcome!

With our first newsletter, we start the task of moving from a multi-person conversation to a functioning scientific collaboration. At the moment, of course, this is still a home-made operation and the structure currently proposed is very much open to negotiation. Here at Loyola we are trying to take the first steps to create the meeting place where ideas can be shared and projects developed. At this stage our goal is very specific – we want to create an organizational structure and a set of preliminary data that will make us competitive for NIH grants. The overall agenda, of course, is much bigger, but for the moment we see grant writing as the immediate challenge.

I realize that all of you are very busy and will therefore try to keep the message in the newsletters focused and straight-forward. Any suggestions on this first effort are certainly welcome. As a self-organizing entity we have to start somewhere, so an organizational structure has been proposed. That structure will almost certainly evolve over time.

As most of you know, the 3 principal leaders for this network are myself, Solomon Ofori-Acquah and Kwaku Ohene-Frempong. We had an initial organizational meeting at Loyola in December and have now written a “statement of purpose” that will be posted on a website for “AfroSickleNet” at Loyola in the

coming weeks (... it has taken a long time for the University to set up the site). To keep the momentum going, I wanted to begin this communication process and define the most effective mode of operating.

As noted, our primary goal is to work toward 1 or more NIH grants. We have the expectation that the NHLBI will announce an RFA this calendar year on SCD research in Africa; if that is not forthcoming we will go ahead and prepare an RO1 for the October deadline anyway. Just based on the conversations we have had already, we have more ideas than could fit in a single RO1. Therefore, sad to say, not all of us will get a seat on that first bus. . . . But given the range of scientific expertise and resources that have been assembled here, there is no reason why we should limit ourselves to a single grant application. Nonetheless, it is important to be clear up front – getting grants is a tough business these days and the science has to drive the design.

At the end of this newsletter we will attach a summary of the structure of the Network itself and the list of participants. My goal here is to make you aware of the current activities and the most immediate priorities.

Finally, anyone wishing to use this newsletter to propose an idea, solicit help or share new information – please feel free to send us a note.

[NB: This “newsletter” is for informal communication among the members of this collaboration; we will generally be on a first name basis. Our apologies in advance for any messages that seem to be written in code.]

Network News: Headlines



- HU study in Nigeria funded by Doris Duke is underway.
- Manuscripts submitted:
 - 1.) Vitamin D levels in SCD patients in Nigeria and Jamaica,
 - 2.) Comparison of clinical measures in SCD patients in Nigeria and Chicago
 - 3.) Genetic variants, HbF levels and rate of hospitalization in Cameroon. (These will be posted on the website)
- Solomon Ofori-Acquah in Kumasi setting up lab and clinical operation.
- B. Tayo visited Yaounde site, and plans trip to Ibadan with L. Hsu this Spring.
- B. Hanchard and R. Cooper to visit Oxford to stimulate MalariaGen collaboration in March/April.

Network News: The Stories

1. We are in the initial phases of the HU study in Ibadan, with contracts in place and IRB approval. We will recruit 2-300 patients, risk stratify based on clinical characteristics, HbF and alpha thal genotype, and conduct an open label crossover study of fixed, low dose HU. (We can send the grant proposal to anyone who wants it.) B. Tayo (LUMC) and V. Gordeuk (UIC) are the PI's.

We have already identified an RFA that might allow us to extend this into measurement of immune response and consequences for hemolysis with HU treatment. – [RFA-HL-14-004 – Ancillary Studies in Clinical Trials \(R01\)](#)
Expiration Date: May 24, 2014

2. Solomon is in Kumasi for a month setting up his lab and developing partnership with clinical hematologists. LUMC investigators are about to start a population-based hepatitis study of ~ 10,000 persons in the near-by town of Obuasi and these samples can be used for DNA and other serum assays related to SCD – particularly measures of hemolysis.

3. Our current most pressing task is to establish a good working relationship with the 3 main clinical sites – Kumasi, Ibadan and Yaounde – and insure that standardized data and biological samples can be collected at each site. We have a short survey of clinical resources that has been circulated and we are standardizing the basic data collection form for clinical characteristics. The data base will be in RedCap. We also hope to generate a set of ~ 50-100 blood samples that can be assayed for our key physiologic measures.

4. We have been joined by a colleague of Guillaume's – Dr. George Ayodo, working at the Center for Global Health and Child Development, in Nairobi, Kenya. This could give us the opportunity to make some comparisons to SCD in East Africa.

5. Nallely Mora and Helen Nde, named above, will be the Project Coordinators at Loyola and provide help with all the documents, communication, etc. As an MPH student at Loyola, Helen hopes to undertake a comparative study of Health Related Quality of Life among SCD and other chronic disease patients in Yaoundé.

6. We are just starting the process of writing a generic Manual of Operations [aka "The MOOP"]. This will be completed in segments as we work through all the issues of IRB, sample collection, lab assays, etc.

So what's next?

I have to confess that the speed with which this has all come together is a bit overwhelming. This is clearly a testament to the expertise that already exists in the collaborating African sites and the interest on the part of US investigators to start carrying out this work in Africa. While we plod through all the required stages of development – IRB, standardized data bases, etc. – it is impossible to avoid the urge to initiate a preliminary study.

We can start preliminary studies for 2 distinct purposes. First, in preparation for an NIH grant, we need to generate evidence of effective collaboration among the key players and we need to show that we can recruit adequate numbers of patients and carry out reliable and comparable lab assays across sites. Second, we could start another small study that could potentially be published, using resources that already exist.

The first of those 2 tasks – creating an effective collaboration – is of course our primary goal. In the meanwhile we are open to suggestions of focused pilot studies that could yield sufficiently interesting results to merit publication. Let us know what ideas you might have and we will circulate them to all collaborators.

Best Wishes! This could well be a turning point for SCD research in Africa. Many thanks for the enthusiastic support from all of you. I have to say, I have done this a few times before, but have never met with this degree of cooperation and seriousness from an international team with this breadth of expertise and experience. I am extremely grateful – even humbled – by the chance to be part of this team.

R. Cooper