Seeding a global movement on neglected diseases

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Universities Allied for Essential Medicines (UAEM) is a coalition of student-led chapters at more than 40 universities in North America and is increasingly recognized as a credible and important partner in the innovation and access to essential medicines movement[1]. However, we are keenly aware of the inherent risks involved when students in the industrialized world try to imagine the needs of resource-poor populations. Thus, UAEM seeks new partnerships with students globally. The partnership serves a dual purpose: to first identify the most pressing local needs and secondly, to mobilize resources North–South to address the needs.

Here, we describe the seeding of our movement in Africa and partnership with the first UAEM chapter in Africa (Makerere University, Kampala, Uganda) on three discrete projects including community-based service, developing new training instruments on neglected diseases and building a credible voice for young scientists throughout Africa.

Partnering with student-led community-based programmes

Community-based education and service (COBES) is a new discipline introduced in the Makerere University medical school and public health curriculum where students learn about diseases affecting the people in their communities. Groups of 8–10 medical and public health students report to different villages all over the country with questionnaires to be completed in interview style by members of local communities (see Figure 1). Questions include queries on the most important problem the community faces, potential solutions and current coping strategies. Surveillance of community clinics reveals the community-specific disease burden as well as discrete information on essential drug availability and treatment practices. Critically, though these reports contain fresh data, they are merely handed in for a grade and forgotten. We decided to use the reports to nucleate a movement on access to essential drugs.

The COBES reports provided the unsurprising finding that malaria remains the predominant concern in northern and eastern Ugandan villages, comprising up to 70% of paediatric visits. However, despite the high prevalence of malaria, first-line anti-malarial drugs (Coartem) remain in short supply. Despite being an essential drug on international and Ugandan lists, it remains out of reach for thousands of villagers. The students find that even when the drug is available there are inappropriate dispensing practices. As a result, local community members turn to traditional medicines and healers, which are relatively cheap.

To address the paucity of Coartem we have adopted a two-pronged approach. First, we have alerted the WHO Essential Medicines programme of this crisis. To our surprise, we found that such notifications of local drug availability are rare. We are devising new research tools with Makerere and the WHO to identify the barriers to Coartem access. Secondly, we have brought the issue to the forefront of our chapters in the global "North" in hopes of addressing the barriers to access head-on. Our successes include reaching the first price concession on an antiretroviral (d4T) in 2001[2] and successfully petitioning the WHO to include a new class of drugs (statins)[3] as essential medicines. However, new linkages with colleagues in local settings provide bidirectional perspectives on whether the "essential medicines" concept is being actualized. If medicines on the Essential Medicines list continue to face price and trade barriers, we hope to document and address these in turn. Hence, these linkages generate research questions that yield crucial data to improve health.

Assembling the first open-access neglected disease curriculum

Interest in neglected diseases is growing globally but there are few publicly available resources for community and self-education. To address this gap we are jointly assembling a neglected disease curriculum for use in universities globally. The course will initially be modelled after a student-led course initiated by students in Cornell University (New York, USA). In this course, we aim to show how concepts from the basic sciences, clinical medicine, economics and population health (nutrition) inform each other as they are brought to bear on an important issue in global health – malaria. We centred the course on the current, highly touted intervention – insecticide-treated bednets. An initial economic and political discussion gives context to the pertinent issues in biology, medicine and population health that will help us form an informed opinion on the potential for bednets as a way to "eradicate malaria in our lifetime" (WHO and Gates

Age: Sex:

Education level:
a) Primary b) Secondary c) Tertiary d) Other e) None

Marital Status:
a) Single b) Married c) Divorced d) Widow e) Widower

1. What are the five most common problems affecting your community?
2. Is there a way in which the above mentioned problems could be solved?
3. If so, could you suggest the possible solutions?
4. In your own view, what do you consider the most important of the problems mentioned?
5. Why do you consider this problem the most important?
6. What do you think is the main cause of the problem mentioned above?
7. As an individual, how are you trying to cope with the problem?
8. How effective has your personal solution been?
9. What challenges do you meet when trying to solve the most important problem you face?
10. Do you consider disease to be one of the problems people face in this community?
11. If so, what are the most common diseases you encounter in this community?
12. What do you think are the causes of the diseases mentioned above?

Figure 1: Needs-based community questionnaire used by Makerere University medical and public health students

Foundation challenge). The full syllabus complete with specified lecture objectives, key review papers and critical case-studies is freely available here: http://skishore.wikispaces.com/NDCurriculum.

Expanding or adapting the course is easily done. Students and local faculty members can simply add on new modules that incorporate the four perspectives. Thus, a 4-week course on malaria can become a 12-week course that includes modules on, say, maternal and child mortality and HIV/AIDS. We aim to deploy the course in five universities in Africa and five in the United States by the summer of 2010, with a goal of integrating the course into standard medical curricula. We aim to do so by working with medical school curricula directors at institutions with UAEM chapters. The digital repository, Health Sciences Online (HSO; www.hso.info), also offers more than 50 000 courses in a diverse range of health topics in English medium for anyone seeking them.

Seedling a global movement on neglected diseases

We believe a bottom-up approach driven by students and young researchers across disciplines is an under-utilized method to impact research priorities. A recent example is worth highlighting. Garemew Guma, a malaria researcher in Addis Ababa, Ethiopia has formed the Young Ethiopian Scientist Network for health research and development (YENet). The idea is that the scientific enterprise should align with society's needs (and vice versa). The group received a certificate of support from the Ministry of Justice of Ethiopia, substantiating their mandate. The group provides a mouthpiece to young, struggling scientists to bring issues to the forefront. The model is emblematic of a more general movement, coined the Young African Scientist Network based in Dar-es-Salaam, Tanzania, that seeks to represent African scientists. Across the globe, the World Association of Young Scientists (WAYS; http://ways.org) provides resources and advice for researchers seeking guidance, equipment, training opportunities and subsidies to attend international research conferences. One third of WAYS' 4000 members are African-based scientists. To assist these young scientists, new groups like AuthorAID (www.authoraid.info) are emerging to help young scientists overcome barriers in publishing, including one-to-one guidance on editing and English.

A student-led campaign can be of great help in addressing neglected disease awareness in the tropics because that's where diseases actually are. One campaign, Loose Change for a Worm-Free World (http://sabin.convio.net/site/PageNavigator/LooseChange) seeks to educate the general public about possible preventive measures, while actively engaging youth on neglected disease control. To be sure, we acknowledge the limitations in trainees' impacting research budgets in the short-term. Our vision, however, concerns building a pipeline of trainees and young researchers with access to resources, insights and thought leaders globally. Our embryonic collaborations will grow, spurring future social innovations that will yield biomedical innovations in the long term. Equally importantly, our linkages ensure that we are aligning our desire to help with where the needs lie. These partnerships should help provide more rigorous evidence on the most pressing gaps when matching up disease burden to current R&D priorities.

Join us in our movement on neglected diseases. ❑

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Key messages

- University-sponsored and student-led community-based programmes in resource-poor settings provide new mechanisms to ensure resources are mobilized and coordinated meaningfully;
- New training instruments, including interdisciplinary neglected diseases curricula, provide capture and mature interest in neglected diseases;
- Young scientist networks are emerging globally to help align society's needs with science (and vice versa).

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Pius Mulamira *is a second-year medical student at Makerere University in Kampala, Uganda. He is interested in a career in biomedical research on neglected diseases and, along with student leaders at Makerere University, has initiated the first UAEM chapter in Africa at his university.*

References

1. Chokshi DA & Rajkumar R (2007) Leveraging university research to advance global health. JAMA 298, 1934-1936.
2. Kapczynski A, Crone ET, & Merson M (2003) Global health and university patents. Science 301, 1629.
3. Magrini N KS (2007) Proposal for the Inclusion of a Statin for the Secondary Prevention of Cardiovascular Diseases in the WHO Model List of Essential Medicines http://mednet3.who.int/EML/expcom/expcom15/applications/newmed/statins/Statins.pdf.