

Capacity building for inherited bleeding disorders in sub-Saharan Africa

Johnny Mahlangu,¹ Kibet Shikuku,² and Livingstone Gayus Dogara³

¹University of the Witwatersrand, National Health Laboratory Service and Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; ²Department of Haematology and Blood Transfusion, College of Health Sciences, University of Nairobi, Nairobi, Kenya; and ³Barau Dikko Teaching Hospital and Kaduna State University, Kaduna, Nigeria

Introduction

Inherited bleeding disorders (IBDs) affect all races in all geographic areas of the world. The World Federation of Haemophilia (WFH) estimates that 70% of the people with IBDs have not yet been diagnosed or do not have access to treatment. Current data show that the majority of these undiagnosed people live in developing countries. A recent global survey from the WFH shows that fewer than 20 of the 50 countries in Africa are members of the WFH and have basic programs to care for people with IBDs.

Study objectives

- Train laboratory technicians to increase capacity for diagnosing people with IBDs in Africa,
- Train professional nurses to increase outreach and nursing capacity in Africa,
- Train physicians to increase knowledge and skill in diagnosing and caring for people with IBDs,
- Conduct knowledge and skill transfer workshops, and
- Establish a care model for people with IBDs in Africa.

Methods and materials

- Individual and small group training sessions were conducted in Johannesburg to train technicians. The hands-on training focused on the resources trainees had at home.
- Nurses were offered training fellowships by the WFH, Novo Nordisk Haemophilia Foundation, and the University of the Witwatersrand to go to train in Johannesburg.
- Physicians were invited as fellows either sponsored externally by various organizations or supported by the University of the Witwatersrand to go to Johannesburg for training.
- A Web site was established (<http://coagulopatiasweb.datasus.gov.br>) to demonstrate a model of care for people with IBDs. The site was constructed by taking into account the roles of various players who provide care for people with IBDs. The aim of the care model was to replicate the successes of other care models in other countries in Africa.

Results

The collaboration and capacity-building activities of the project from 2010 to 2018 resulted in:

- Training 40 technicians from 12 countries in Africa (Figure 1),
- Training 15 nurses from 10 countries in Africa (Figure 2),

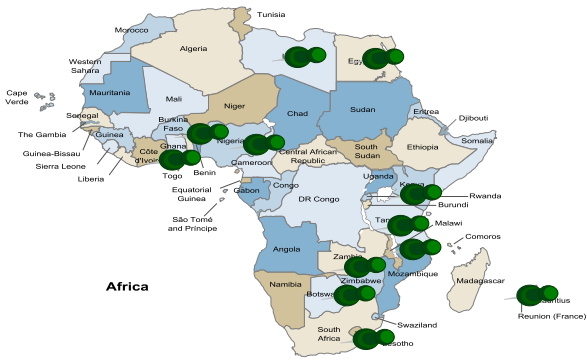


Figure 1. Technician training by country.

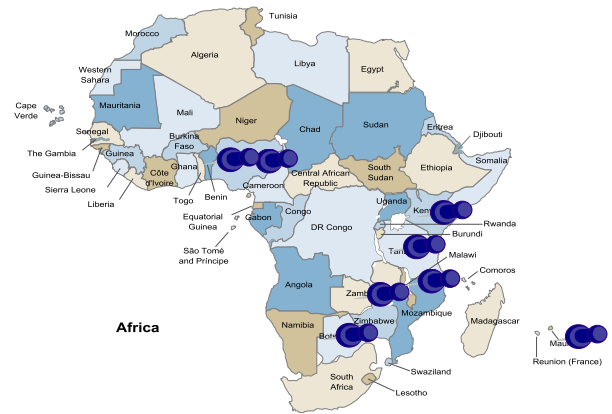


Figure 3. Physician training by country.

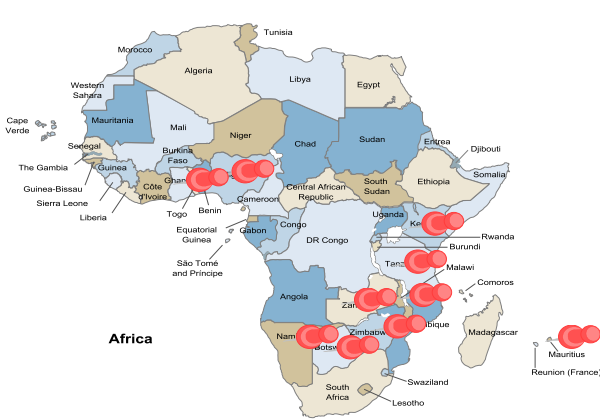


Figure 2. Nurses training by country.



Figure 4. Training workshops by country.



- Training 12 physicians from 8 countries in Africa (Figure 3), and
- Conducting 13 training workshops in 12 countries in Africa (Figure 4).

Impact

From 2010 to 2018, our intra-Africa collaboration and capacity building had the following impacts (Figure 5):

- More than 2000 people with IBDs have been diagnosed in sub-Saharan Africa by trainees who participated in the various training programs over the last 9 years.
- Ten hospitals are now able to make an IBD diagnosis.
- Five national member organizations have been accredited by the WFH.

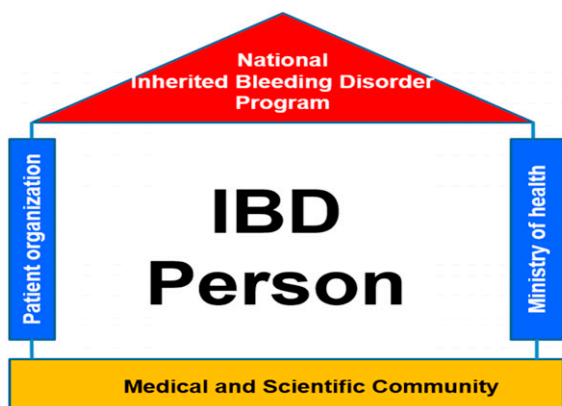


Figure 5. IBD optimum care model.

- Six countries now have functional care models involving all stakeholders.
- Five countries have the capacity to procure clotting factor concentrates as a result of being able to diagnose IBDs.
- Eight countries have established hemophilia treatment centers.

Acknowledgments

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Authorship

Conflict-of-interest disclosure: J.M. served as a consultant for Baxalta, Chugai, CSL Behring, NovoNordisk, Laboratoire Francais du Fractionnement et Des Biotechnologies SA (LFB) Pfizer, Roche, Shire, Spark, and Takeda; received research funding from Baxalta, BioMarin, CSL Behring, Freeline Therapeutics, Novo Nordisk, Novartis, Pfizer, Roche, Sanofi Genzyme, Shire, Sobi, and uniQure; received honoraria from Takeda; and served on a speaker's bureau for Baxalta, CSL Behring, Novo Nordisk, Pfizer, Roche, Sanofi Genzyme, Shire, Sobi, Spark, Takeda, and the World Federation of Hemophilia. The remaining authors declare no competing financial interests.

Correspondence: Johnny Mahlangu, Department of Molecular Medicine and Haematology, School of Pathology, Faculty of Health Sciences, Area 454, Room 50, Charlotte Maxeke Johannesburg Academic Hospital, 7 York Rd, Parktown 2193, South Africa; e-mail: johnny.mahlangu@wits.ac.za.

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