

"SHARING EXPERTISE THROUGH TWINNING EXPERT CENTRES."

OCTOBER 2022

Interview with Professor Johnny Mahlangu, Clinical Haematologist and Head of the School of Pathology – the University of the Witwatersrand – and National Health Laboratory Service, Johannesburg, South Africa

MEET PROF. MAHLANGU



Over 300 million persons live with a rare disease worldwide, but due to the vast dispersion of experts on the subject, **expertise on each rare disease is often hard to access**. Without the necessary expertise, many people with a rare disease remain undiagnosed and cannot access the basic care and treatment they need. This is especially true for many low-and-middle-income countries whose health systems can not cope with competing demands on limited resources.

However, health systems can be strengthened to build expertise and offer local access to timely diagnosis and care. Much can be learnt from the African bleeding disorders community.

We welcomed Prof. Johnny Mahlangu to share his experience with the Charlotte Maxeke Johannesburg Academic Hospital in South Africa and the University of the Witwatersrand. The hospital was successfully accredited by the World Federation for Haemophilia (WFH) as one of 50 **International Haemophilia Treatment Centres (IHTC)** and is participating in the **WFH twinning programme** with several hospitals in Mauritius.

This conversation is the second of a series of interviews with members of the Panel of Experts, a group of over 200 clinicians, researchers, administrators, academics and civil society leaders, supporting the development of the [Global Network for Rare Diseases](#).

INTERVIEW

What is the WFH Expert Centre Twinning Programme ?

The WFH twinning programme **connects two expert centres from across the globe** to discuss cases and build competency on rare bleeding disorders together. It is a very practical solution to address a common need and make skills and knowledge exchange accessible where needed.

Four years ago, we established a twinning between South Africa and Mauritius, which has been very successful. We have now set up a diploma in Mauritius to support the development of the next generation of experts in rare bleeding disorders, who will continue to exchange knowledge with the Charlotte Maxeke Johannesburg Academic Hospital in South Africa.

Can you tell us more about the objectives of the WFH Expert Centre Twinning Programme and its achievements so far ?

As an **International Haemophilia Treatment Centre (IHTC)**, we aim to provide onsite knowledge transfer, conduct online case reviews and share experiences in regional training workshops.

Our centre supports exchanges of healthcare professionals to train and gain expertise in the diagnosis and management of rare bleeding disorders. This could be for two weeks or up to 12 months. We also secure funding support for the exchange programme from a variety of sources including the WFH, American Society of Haematology, NovoNordisk Foundations and ISTH.

To date, we have trained over 40 nurses, laboratory technologists, general practitioners and haematologists from across the African region. Throughout the COVID pandemic, we continued the exchange online. We have three more fellows coming to the centre in 2022 and another 3-4 in the new year.

Is your centre also active in other African countries?

We continue to work with a **growing network of experts from Tanzania, Zambia, Malawi, Nigeria, Mozambique and more**. Every week we discuss specific patient cases, and we follow up with patients who have already been treated at our centre and returned home. We have participated in four workshops in Dubai, Senegal, South Africa and Kenya. There were over 60 experts from 17 countries connected in the last workshops.

The **WFH humanitarian programme** gives access to therapies in countries with limited access. The workshops are a big event that provides a rich learning space for experts to share their real-world experiences and learn from each other. The workshops help to show the effectiveness of treatment which in turn helps to gain support from the **Ministry of Health** to continue these treatments.

The aim is to ensure that prophylaxis treatment becomes a policy priority as it reduces the burden of disease, reduces the number of demands on hospital services and prevents disease complications.

What have been the benefits for patients?

With a growing number of experts in rare bleeding disorders, we are seeing **a 22.9% increase in the number of people identified with haemophilia between 2016 and 2018 (*1)**, and the number of patients treated with donated CFCs increased from 1123 to 5501 (*2)

We are also seeing **policy changes happen**, but it is still slow. Mauritius is the only country in Africa where the government provides a subcutaneously administered prophylactic agent, which the other 51 countries are not providing.

(*1) *Improving access to hemophilia care in sub-Saharan Africa by capacity building_- Saliou Diop, Assad Haffar, Johnny Mahlangu, Irene Chami, Steve Kitchen, and Glenn Pierce - Published online 2019 Dec 6. <https://pubmed.ncbi.nlm.nih.gov/31809543/>*

(*2) *Capacity building for inherited bleeding disorders in sub-Saharan Africa - Johnny Mahlangu, Kibet Shikuku, and Livingstone Gayus Dogara- Published online 2019 Dec 6. <https://pubmed.ncbi.nlm.nih.gov/31809546/>*

Final words to conclude?

Twinning expert centres is a solution to respond more effectively to Persons Living with a Rare Disease around the world. We are only one example of two regions sharing knowledge on one specific disease. But, **I'm convinced all PLWRD would greatly benefit from this programme extending to more centres and more disease areas.**

I strongly believe in the **valuable outcomes of the development of the Global Network for Rare Diseases**, and I'm proud to be part of the landmark project in collaboration with the World Health Organization (WHO).



For more info on the WFH Twinning center programme :

- **World Federation of Hemophilia Website**
- Reach Paper -Improving access to hemophilia care in sub-Saharan Africa by capacity building_ and Capacity building for inherited bleeding disorders in sub-Saharan Africa



Stay tuned for the next Global Network for Rare Disease expert article



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