

## Morocco: West Africa gets educated – May 2019

Tanya Collin-Histed reports...

As part of the IGA commitment to improve 'Gaucher patients' access to optimal diagnosis, treatment and care', the IGA CEO, Tanya Collin-Histed is a member of FYMCA's faculty to educate doctors around the world, with a particular focus on developing countries to improve diagnosis and provide care solutions whilst be aware of access to resources in countries.

On the 21st May, Tanya flew to Rabat, Morocco and took part in a three-day educational programme that attracted 41 delegates from all over West Africa including Ghana, Morocco, Tunisia, Kenya, Rwanda, Niger, Ivory Coast, Congo and Mauritania.

The programme focuses on metabolic diseases, rare and lysosomal disorders with a link to Gaucher, Fabry and MPS II as part of Takeda's charitable access programme which was launched in a number of African countries for 2019 following a similar three day meeting in Botswana last June for doctors from other parts of Africa.

By educating doctors to think about metabolic diseases when patients present to them and giving them the knowledge of how to test for certain diseases and what in some cases simple treatments can be given is very powerful and can prevent many deaths or prolonged diagnostic journeys for patients.

The IGA presented on patients' advocacy outlining how this is about the different aspects of the patients' journey and demonstrating how powerful patient advocate can be to support the development of the infrastructure in a country to improve the lives of patients. An example of this was the last two speakers of the day from Dr Elikplim Ahiable, a doctor and Samuel Agyie Wiafe from Ghana who become interested in rare diseases in his job as a psychologist when he met a family with a number of children with a rare disease. Since then they have been the catalyst to bring the different stakeholders together in Ghana to improve awareness, diagnostics, information, support, clinical care through the creation of the Rare Disease Ghana Initiative.

After the educational meeting Tanya met with the Head of the Morocco patient group, that joined the IGA in 2018 to discuss a number of issues affecting Gaucher patients in Morocco and to seek solutions by working together.

This type of collaboration demonstrates how effective working together is and how great things can be achieved by sharing knowledge and resources.