

Botswana event: FYMCA Medical, 1-3 July 2018

Tanya Collin-Histed reports...

I was invited to be part of the faculty for a meeting in Botswana of doctors from all over Africa; 36 doctors attended from 14 different countries, including: Ghana, Nigeria, Sudan, Botswana, Mauritius, Ethiopia, Kenya, Malawi and Lesotho.

The model for this meeting was to educate doctors on rare metabolic conditions, looking at how to diagnose and treat patients with what is available in their country.

The meeting was videoed and will be uploaded to a platform where all the delegates can access. There will also be an exam, and after a year, a second meeting will be held to focus on specific issues that have been highlighted by the delegates, i.e. diet, pain relief, psychology.

This meeting was organised by FYMCA Medical, a for-profit organisation with a focus on improving rare disease education and services for doctors, patients and patient organisations in the developing world.

Throughout the three-day meeting, the doctors attending highlighted previous patients that they are now thinking may have a metabolic disorder.

I made a presentation at the meeting about the role and value of patient organisations and spoke about the role of a national patient organisation and also the work of the EGA.

Prior to the meeting, a pre-meeting questionnaire was sent out to everyone and I had the opportunity to include a few questions regarding patients, patient organisations, diagnostics and registries, etc. which will help the EGA to better understand the situation in these African countries.

I will now write to all the delegates who attended the meeting to identify potential African patients/family members that could attend the patient huddle at the September's RAREX meeting in Johannesburg where we will support 27 participants through a grant from Care Beyond Diagnosis, a US non-profit organisation the EGA is working closely with.