

African Taskforce Report 2019

EXECUTIVE SUMMARY

There are multiple problems unique to Africa which limits the care that rare disease patients receive across the continent. The African Taskforce is a joint venture set up by FYMCA Medical Ltd (a for profit UK based expert medical education company) and Care Beyond Diagnosis a USA based non- profit organization) to connect likeminded clinicians, patient groups and policymakers to firstly identify common problems faced in establishing rare disease programs in resource limited countries across the African continent. This initiative was run on the Within3 digital platform to gauge maximum engagement and minimal loss of time.

Invitations were sent out to 27 delegates from 19 countries and in spite of the limitations of the communications networks 22 delegates engaged to generate the following responses lead by 6 moderators stimulating the different conversation topics. The views of 16 African countries are represented in this report and they were supported by patient groups from United Kingdom and Canada.

Key issues:

1. Only 10 % had a definition of rare diseases and most used current international definitions rather than continent appropriate definitions.
2. Only 11% had a rare disease policy in place but 100% believed they will have one within 5 years.
3. Access to diagnostic investigations for rare disorders were present in some form in 75% of the countries and all have the ability to send sample out of country but the process to achieve this is complex in many cases.
4. Limited genetic testing was available in 65% of the countries.
5. Rare disease awareness was generally poor with politicians the group with the lowest awareness of rare disorders.
6. Training for rare disease were available in 55% of the countries and was mostly simple and linked to endocrinology training programs.

7. Clinical guidelines were deemed to be very important by 80% of respondents but only 10% had some guidelines in place for rare disorders and no one was aware of any network to develop local guidelines.

8. Exceptional patient organisations were also present and were actively trying to unite patient groups across the continent however public and political support for patient groups were generally lacking, which creates a further obstacle for new patient groups. These challenges many times lead to poorly developed groups which can tend to focus on one specific disease related to group leader rather than wider rare disease issues.

9. In rare disorders the term “let no patient be left behind” is frequently used but from this project we sensed that like one of the patient advocates said “let no country be left behind” maybe for Africa we must say “let no continent be left behind to care for its rare disorder patients”

There are many issues facing patients with rare disorders in Africa but there is a great willingness to resolve these issues and deliver the care patients deserve but the apathy and misconceptions about Africa needs to be addressed and we all hope this is a step in the right direction.

The full report will be published in a peer reviewed journal and any questions or comments can be addressed to info@fymcamedical.co.uk.

This report was developed with contributions from clinicians and patient groups from the following countries; United Kingdom, United States of America, South Africa, Canada, Ghana, Botswana, Kenya, Nigeria, Sudan, Tanzania, Rwanda, Mauritania, Niger, Ivory Coast, Congo Brazzaville, Tunisia, Cameroon, Zimbabwe and Senegal.