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Background

- There are a paucity of educational programs aimed at increasing awareness of rare disorders in developing countries.
- This educational deficit has a direct impact on patient care resulting in delayed diagnosis, misdiagnosis and increased infant mortality.
- Since the 2017 inception of the FYMCA Medical global educational initiative, programs have been offered in Panama, Botswana, Kazakhstan and Morocco focusing on raising the awareness of metabolic disorders.
- Programs are made possible through industry-sponsored educational grants.
- To date, 158 doctors have been trained representing 40 countries.
- As a direct result of the FYMCA initiative, 227 patients with rare genetic disorders have been identified. Herein, we report on the experience in Africa.

Methods

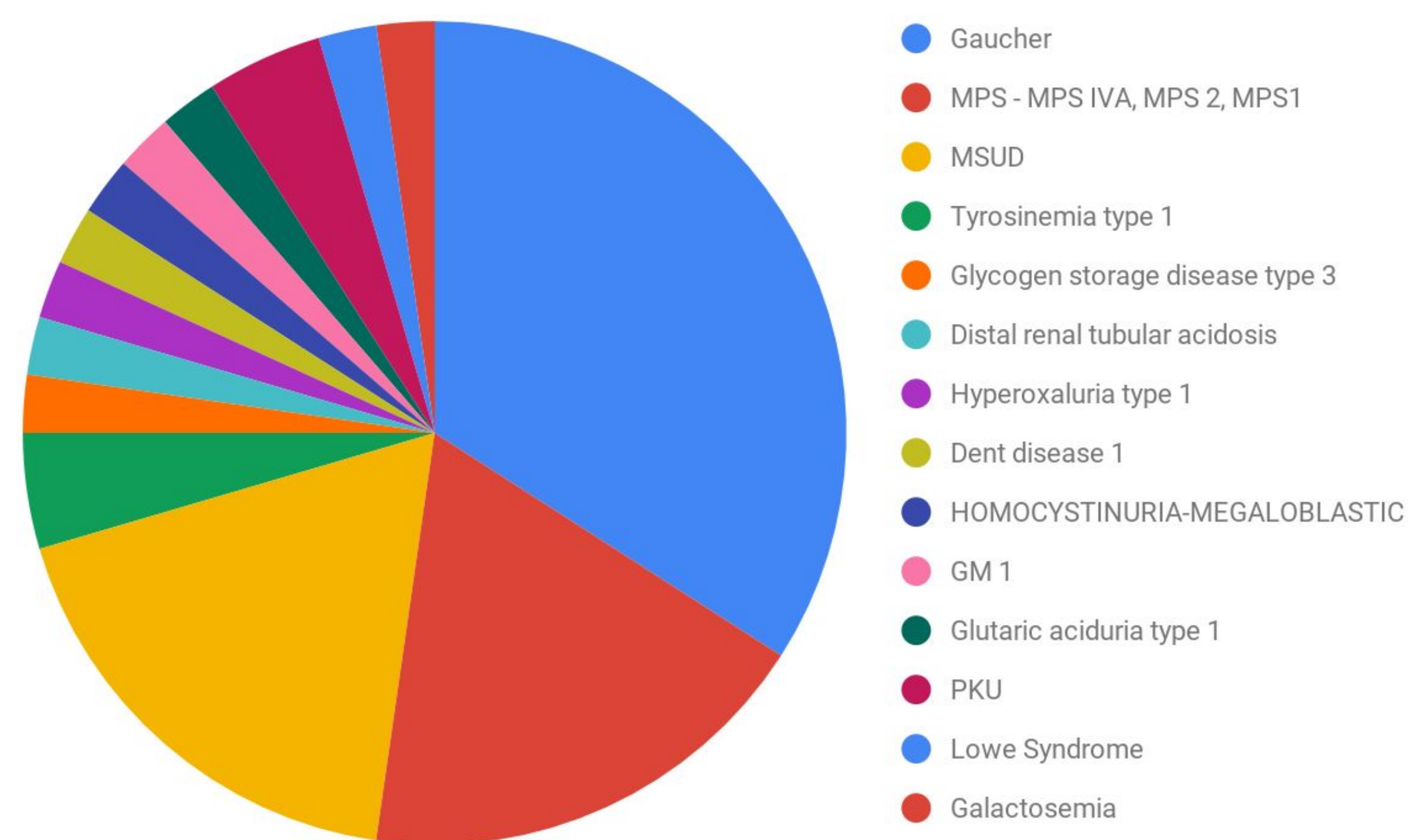
- FYMCA, a for-profit company, hosted a 3-day educational program in Botswana, Africa in June 2018, for 38 delegates representing 14 African countries and in May 2019 in Morocco for 41 delegates from 10 African countries (Figure 2).
- The comprehensive agenda included insights for diagnosing IEM, LSDs organic acidurias, organic acidemia and UCDs.
- Delegates continue engaging with FYMCA faculty via virtual Grand Rounds and share challenging medical cases. Clinicians report the number of newly diagnosed cases of rare disorders as a direct result of the educational program.



Results

- By August 2019, a total of 76 confirmed cases of rare disorders were identified, in spite of the severe lack of diagnostic facilities (Figure 1).
- The commonest disorders identified are Gaucher disease, galactosemia, mucopolysaccharidoses (MPS) and maple syrup urine disease (MSUD).
- The most diagnoses were made in Sudan and Tanzania and very significant changes to medical education and health delivery have been initiated.
- This greater awareness have lead to two centers starting to train additional clinicians and allied health care professionals.
- An African task force has been setup which explored all the issues faced in Africa collectively and it is planned to move this into action with multiple partners.

Figure 1



Conclusions

- FYMCA has demonstrated that dedication and commitment to hosting and providing educational programs to developing countries can significantly impact diagnosis, patient care and outcomes.
- FYMCA and Care Beyond Diagnosis, the non-profit partner, believe that every individual diagnosed with a rare disorder has the right to first-class care and support, regardless of location or economic status.

Figure 2



Professor Chris Hendriksz, founder of FYMCA shares “It was amazing to see rare disease patients in the new declaration of universal healthcare and the strapline, “Let no patient be left behind.” However our work in Africa suggested the whole continent has been left behind when considering rare disease patients. Help us to change this in 2020 and the subsequent years.”