

Together Improving Haemophilia Healthcare in Kenya

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Introduction:

Kenya Haemophilia Association(KHA) was founded in 1979 and reregistered in 2014 as the national patient organization to create awareness, capacity building of healthcare professionals, improve diagnosis and treat patients with haemophilia and other bleeding disorders. Together with the ministry of health it seeks to ensure sustainable provision of quality healthcare to patients. Only 10% out of 4300 haemophilia patients have been diagnosed and being managed at Kenyatta National Hospital and Moi Teaching and Referral Hospital. KHA brings together patients , parents and healthcare professionals to aid in advocacy, diagnosis and treatment.

Objectives:

To unite the patient population under one registered umbrella organization , develop a constitution and call for elections, create a web based national register , develop a five year strategic plan , create awareness through advocacy, diagnosis and treatment.

Methodology:

An interim voluntary executive committee was formed with various meetings involving all stakeholders held. Writing committees for the constitution, national strategic plan and development of the national register were formed. Advocacy programs for different groups and celebrations of world haemophilia days were done. Assessments performed revealed that 4% of the patients had been diagnosed, 30% lived beyond 19 years , 90% deaths from unsafe circumcision practices, 60-70% living with co-morbidities from haemophilia , factor concentrates availability of 0.006IU per capita, a single hospital with 2-4 clinicians and three disjointed patient associations. Haemophilia was not considered a health priority due to scarce data and historical focus on communicable diseases.

Results and Achievements:

With 2 year advocacies; 420 healthcare providers were trained, two hospitals empowered to test and manage patients, 45 new patients diagnosed, a national register with 428 entries, a patient association registered, 14 television and 11 radio stations awareness campaigns, 100 short message enquiries made and increased interest by professionals to work with the program was realized.

Conclusion:

Prudent leadership, stakeholder inclusion and transparency are key for quick progress and sustainability of our program.

