Title name: Outreach Programs and Advocacy of Sickle Cell Disease Care in Kenya

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KENYA & Sickle Cell Disease (SCD) (1)

• Kenya: East Africa
• Approx. Population: 45,000,000
• Western and Coastal Regions mostly affected
In Kenya, SCD is the hereditary hemolytic anemia accounting for over 15% of all childhood anemia (Kasili et al., 1982).

The occurrence of sickle cell trait varies from less than 1% among the ethnic groups of the Kenyan central highlands to as high as 20-25% in those inhabiting the malaria holoendemic coastal and the lake belts of the country (Kasili et al., 1982).

A national survey of SCA patients in Kenya was done between Nov 1987 to May 1990, revealing 3605 cases, 80% of which belonged to Luo and Luhya ethnic origins (Aluoch, et al. 1993). These communities reside near and around Moi Teaching and Referral Hospital (MTRH).
AMPATH Hematology Program

- Initiated in 2011
- Support from the Indiana Hemophilia and Thrombosis Centre (IHTC).
- Embarked on research, outreach SCD care and educational programs.
- Focus on health institutions as well as communities to create awareness on SCD.
Education & Training

- Targeting multidisciplinary teams of health workers across Kenya
- Educate and train patients on the management of SCD
- Focus on education of the disease, testing and treatment/care.
Community Education & Advocacy

- Local communities are educated and the creation of awareness about SCD is provided.
- Families and PWSCD are involved in creating awareness.
- Platform for health worker vs community sensitization.
School & Home Visits

- Educate children and parents, including teachers from various schools about SCD
- Teacher and student relations to understand SCD and its management.
- Increase awareness and advocacy
Diagnostic Services

• Provision of high quality Sickle Cell Disease diagnostic services

• Iso Electric Focusing (IEF) in the New Born Units (NBU) and Immunization Clinics

• HB Electrophoresis (Confirmatory testing for SCD)

• Pilot Point of Care (POC) test (Sickle Scan)
Treatment Medications

- Hydroxyurea 500mg
- Penicillin Tablets 250mg
- Penicillin Syrup 250mg
- Paludrine Tablets 100mg
- Folic Acid
- Pneumococcal and Meningococcal Vaccines
Recent Research Studies

• FEASIBILITY AND EFFECTIVENESS OF HYDROXYUREA IN A SUB-SAHARAN AFRICAN POPULATION WITH SICKLE CELL DISEASE (2011)

• VALIDATION OF HEMOTYPE SC™ DIAGNOSTIC TEST FOR SICKLE CELL DISEASE IN NEWBORNS AND INFANTS AGES 0 TO 12 MONTHS (2017/2018)

What It Is
A Point-of-Care Diagnostic Test for Sickle Cell Disease (SCD).
Outreach Clinical Care Program

- Provision of high quality Sickle Cell Disease care and treatment.
- Consultation services to patients in the comprehensive care clinics
- Interactive sessions to healthcare providers during ward rounds
Patient support

• Provide support to the patients through community leaders.

• Interactive sessions with families and patients

• Partnerships with Kenya Sickle Cell Disease Foundations

• Creation of social media groups through WhatsApp for information
Challenges & Obstacles

• Lab (Consistency & Turn around times)
• Patient follow up after testing & results
• Socio economic challenges for patients (costs related to tests, medications & travel to clinics)
• Collaborative challenges with rural hospitals on integration of POC programs
• Sustainability of funding for the outreach clinics

Way forward

• Advanced training & supervision to improve laboratory services
• Immediate & consistent communication follow up to families
• Waiver systems, Revolving Fund Pharmacy (RFP) & transport reimbursements
• Continued trainings and follow up of true partnerships
• Involvement of County Governments for sustainable clinical programs
Community Service
Results

• More than 700 healthcare providers in Kenya have been trained
• 2 County and 1 Sub County hospitals initiated in the comprehensive outreach care clinics.
• More than 50 local healthcare providers trained and administering care.
• 20 Schools have been visited and trained, 20 patient home visits have been done.
• During the visits and trainings emphasis is made on ensuring proper understanding of Sickle Cell Disease and its management.
• A good referral system has been developed for Sickle Cell Disease with a robust patient follow up system.
• Health professional, nurses, doctors from all over the country have been educated by experts in the care of Sickle Cell Disease patients.
Conclusion

• Awareness about Sickle Cell Disease in Kenya has been increased.
• This has resulted in a greater number of patients being treated with prophylactic penicillin and antimalarials where indicated, and greater access to prescribing of hydroxyurea.
• There is also improved knowledge about management of patients when hospitalized acutely.
• Increased education, training and capacity building in Kenya.
• It is anticipated that these measures will lead to a reduction in morbidity and mortality from Sickle Cell Disease.
References


• British journal of hematology, *HemoType SC™*Charles T. Quinn,1 Mary C. Paniagua,1 Robert K. DiNello,2 Anand Panchal, and Mark Geisberg2,1Cincinnati Children’s Hospital Medical Center, Cincinnati, OH, and 2Silver Lake Research Corporation, Azusa, CA, USA
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