INTRODUCTION:
• Study country – Kenya
• No definition of a rare disease
• Very minimal genetic set-up in the country

BACKGROUND OF AUTHOR:
• Co-founder of Rare Disorders Kenya (RDK), a patient organization that provides a united voice for the rare disease community in Kenya
• Mother to two children with different rare conditions namely: Megalencephaly Capillary Malformation (MCM) and Ring 18 Chromosome

METHODS:
➢ Rare Disorders Kenya (RDK):
  • Patient led organization formed to raise profile of the different rare diseases in Kenya
  • Creating awareness especially through the annual Rare Disease Day campaigns
  • Offer emotional and psychosocial support to members
➢ Local stakeholders
  • Policy and decision making in (rare) disease matters with the Ministry of Health
  • Engaging pharmaceuticals in (local) awareness and research projects
➢ International stakeholders
  • Become affiliate members of international rare disease bodies
  • Avoid reinvention of the wheel by seeking assistance in RDK setup and functions

RESULTS:
• A registry database that will be the base for the national definition of a rare disease
• Equitable healthcare for all especially the rare disease community in Kenya
• National awareness resulting in reduced stigmatization of persons living with rare diseases

CONCLUSION:
Normalization of living with a rare disease can only be achieved if there is awareness, negative cultural practices and/or superstitions are made obsolete and there is healthcare to support those affected by rare diseases.

“If you want to go fast, go alone. If you want to go far, go together.”
(African Proverb)