

POSTER 225

THEME 7	RARE DISEASE PATIENT GROUPS INNOVATIONS
TITLE	WHEN LIGHTNING STRIKES TWICE, DIFFERENTLY
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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)*