

STEPPING STONES (KENYA)

Step By Step, Stone After Stone, Together We Shall Overcome

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ABOUT

- Stepping Stones is a patient organization support group for parents of children with rare diseases and/or special needs. It is a forum whereby parents can share, vent, ask, and most importantly feel like they are not alone. It is not geared to any specific disability, neither is it prohibitive to parents only. It is a place where anyone afflicted by a child with special needs (or even individuals themselves) can feel welcome and at home.
- As the name suggests, Stepping Stones is meant to help fellow special needs parents grow in the journey that they have been called to make. It is for each individual to be a stepping stone to the other, to assist one another go a mile further.
- It was founded in August 2013 out of a need of parents coming together to support one another. It consists of not only parents but also experts ranging from doctors, physiotherapists, psychologists among others.

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OBJECTIVES

The objectives of the Stepping Stones include but is not limited to:

- Offer emotional support to parents of children with rare diseases and/or special needs
- Create a space to share the experiences of people with various rare diseases/genetic disorders
- Provide linkages for rare disease patients to necessary support systems
- Offer psychosocial support to parents through liaison with other professional bodies
- Create awareness whilst providing much needed information on rare diseases
- Offer training opportunities to parents through partnership with other professional bodies.

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SOME OF THE RARE DISEASES REPRESENTED IN KENYA

- Hemihyperplasia (hemihypertrophy)
- Ring 18 Chromosome
- Muscular Dystrophy:
 - Limb Girdle
 - Duchenne
 - Spinal Muscular Atrophy
- Albinism
- Hereditary Angioedema
- Gaucher
- Multiple Sclerosis

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REALITY OF RARE DISEASES IN KENYA

- Accurate diagnosis often takes 10-15yrs
- Inadequacy of specialized healthcare providers.
- Useful, reliable and timely information may be hard to find.
- Inadequate investment in research for orphan drugs/conditions
- Highly priced treatment plans
- In developing countries, these problems are compounded by other resource limitations.

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CHALLENGES OF RARE DISEASES IN KENYA

- Absence of any database
- Delayed diagnosis due to lack of new-born screening
- Stigma and discrimination in society
- High medical costs for management, genetic or pre-existing conditions rarely insured
- High risk of psychological issues arising in the patients and/or their caregivers

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