

Rare Disease Day:

The Kenyan Perspective



Christine Mutena
Co-Founder
21st October, 2020

Rare Disorders Kenya



Patient-led organization that creates awareness and advocates
for rare diseases in Kenya

Rare Disease Day in Kenya

- 2014 – First ever RDD
- 2014 patients as a target audience vis a vis 2018 policy makers as TA
- 2020 - Successfully partnered with MoH
- Social media a huge channel of disseminating information to the public
- Rare Disorders Kenya (RDK) was born in 2018 out of these events
- About 40 different conditions represented under RDK



Our RDK Objectives

- ▶ Raise awareness on rare diseases in our country
- ▶ Improve the lives of PLWRD
- ▶ Work with the national government and other stakeholders
- ▶ Improve data collection: disease registry



Challenges

- 2014 – uncharted territory
- Financial constraints
- Inexperience
- Patient privacy in advocacy
- Access to policy and decision makers in the health industry



Social Media Tools:



Twitter / Facebook / LinkedIn - @RareDiseaseKE

- ▶ Uniformity across all platforms
- ▶ Ease of access to high ranking people via SM
- ▶ Sharing of info globally at a click of a button

Where We Are Now



- ▶ RDK now fighting for the rights of PLWRD in Kenya
- ▶ RDK recognized by some mainstream media
- ▶ Partnerships with local stakeholders in the RD community
- ▶ Partnerships with international partners including RDI



2019 RDD



2020 RDD





Thank You!



Rare Disorders Kenya (RDK)
KCB Building, Rm. 207,
Garage Road, Off Dar es Salam Road,
Nairobi, Kenya
Tel : +254 701 025 753

www.rarediseasekenya.org
info@rarediseasekenya.org

Twitter: @RareDiseaseKE
Facebook: @RareDiseaseKE