Rare Disease Day:

The Kenyan Perspective



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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 unchartered 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



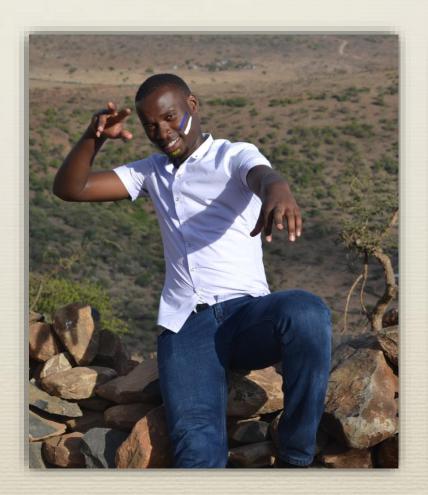




2020 RDD



2019 RDD









Thank You!



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