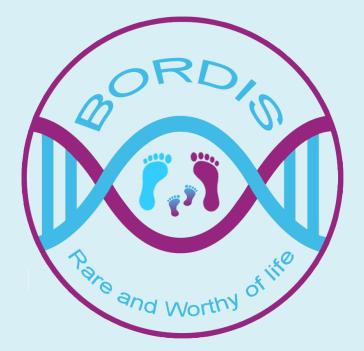
# Botswana Organisation for Rare Diseases



Eda Selebatso

Founder & Chairperson





## **About BORDIS**

# CLIMBING AND CLAWING OUT OF THE GRAVE !!!!!!!!!!



# WHY BORDIS....







# **About BORDIS**

- a registered NPO
- voice of rare diseases patients in Botswana
- membership is open to all



# **Strategic Direction**

#### **VISION**

• To create an environment that enables Rare disease patients to thrive

#### **MISSION**

• To build strong <u>collaborations and networks</u> in Botswana and globally to harness resources and any necessary inputs to <u>ensure access to diagnosis, right treatments</u> and management for Rare disease patients in Botswana.

#### **VALUES**

- BORDIS' work will promote good HEALTH for rare disease patients.
- BORDIS is committed to exercise **INTEGRITY** in all work done towards achieving BORDIS vision.
- BORDIS believes **LIFE** is a God given gift and we will work to preserve it and enable the Rare lives to thrive as long as that gift of life is available.
- We acknowledge the hardships that rare disease patients and families face on a daily basis and BORDIS will journey with them and support them through **LOVE** to lighten their burden.



## **OBJECTIVES**

- 1. To support and advocate for equitable diagnosis, access to appropriate quality health care and treatment for Rare Diseases patients.
- 2. To offer patients and families affected by rare diseases the necessary support and maintain their dignity and respect.
- 3. To work closely with the Ministry of Health in Botswana in policy development and any necessary documents that guide in management of rare diseases in Botswana.
- 4. To be the primary source of information on rare diseases in general and in Botswana. In addition the society will develop and disseminate information to patients, parents, carers and the general public about rare diseases.
- 5. To facilitate capacity building and networking opportunities for health care professionals to ensure better identification and management of rare diseases in Botswana.



## **CHALLENGES**

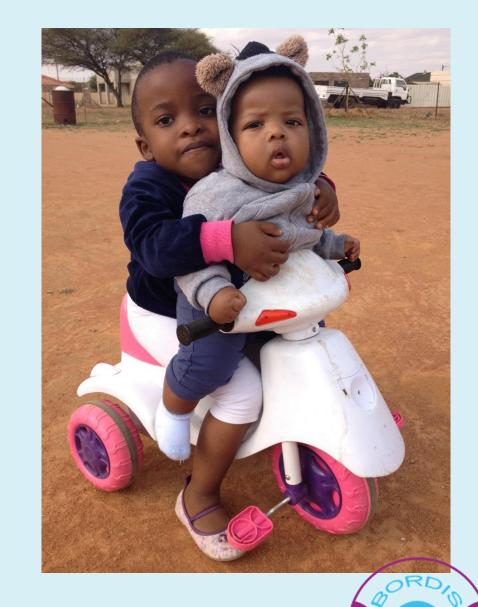
- VERY limited knowledge on rare diseases
- No policy or any guiding documents
- Biased health care system
- Inadequate infrastructure
- Limited funding
- LOCKED doors





## Achievements

- Diagnosis
- Access to treatment
- Brand, website
- Stakeholder engagement
- Membership growth
- Training (members and health professionals)
- Awareness creation ...radio, tv, social media
- fundraising



# CONCLUSION

#### **RARE AND WORTHY OF LIFE**



