

The effects and issues affecting rare patients in Africa due to inadequate access to drugs or medical trials

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The plight of rare diseases patients or Rare Butterflies as we call them in Africa is set against the backdrop of a continent dealing with socio-political and economic conditions that adversely affect vulnerable groups such as rare patients in need of specialist care. The condition of the continent as a whole leaves a gaping hole where those most vulnerable are susceptible to falling through the cracks, this is why non-profit organizations such as Rare Diseases Lesotho Association and the Rare Diseases Initiative exist. These entities exist to drive an active mandate to ensure that everyone, especially Rare patients receive adequate healthcare services and support, while maintaining a firm stance in the promotion of their equitable rights to medical care with dignity at the forefront. This study focuses on the inadequacies and shortfalls of the systems that exist in Africa in reference to rare patients receiving specialist care, accessing lifesaving medicine and potentially life altering medical trials as part of their treatment

plans. It is no surprise that the continent as a whole is grossly unprepared and overwhelmed with the need for specialist care facilities and lifesaving orphan drugs and treatment plans, and this sets us back a couple of years in the healthcare system and seek to address these issues through a pragmatic problem solving outlook on the issues illustrated within the scope of access to healthcare for Rare patients and the red tape that exists within.

Biography

Nthabeleng P Ramoeli is the founder of Rare Disease Lesotho Association which was founded in October 2017. She is a young woman with Ehlers-Danlos Syndromes (EDS) and Seeng Nchai, a mother with child with a rare disease. The purpose of the Organization assists all patients affected by rare diseases to access treatment and support care for improved health and quality of life..

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Received : March 15, 2022; Accepted : March 21, 2022; Published: June 30, 2022