

## **AFRICAN ALLIANCE FOR RARE DISEASES (Africa-Rare.org)**

### **TERMS OF REFERENCE**

The **AFRICAN ALLIANCE FOR RARE DISEASES** (The Alliance) is a multi-stakeholder group of organisations that engage in rare disease care and control in Africa, brought together to establish an alliance that seeks to collaborate, co-ordinate and advocate on behalf of rare disease patients in the African continent.

Over 350 million people are affected by rare diseases globally. 80% of the 7000 rare diseases are genetic in order, and 50% appear within the first year of life. Only 5% of all rare conditions have treatment available, which leaves 95% of patients only able to access supportive care for improved quality of life. A lack of prevention, delayed diagnosis as well as lack of reliable diagnostics further decrease these patients access to suitable treatment of rare conditions.

There is also currently no Rare Disease registry in Africa, which underreports the current statistics and data in terms of rare diseases contribution to the under 5 mortality rates. Whilst the global prevalence is in itself significant, it is universally accepted that the numbers are under reported. The lack of universal coding and classification for rare conditions makes accurate cost analysis impossible. For organisations working within rare disease advocacy, we have over the last few years witnessed a marked and ever increasing demand for relevant support services. All of the statistics and facts point to one conclusion: rare diseases are a significant and growing public health challenge in Africa and across the globe.

The Alliance is a voluntary group of members that will meet annually to discuss thought leadership matters pertaining to rare diseases in Africa. The membership is guided by a Terms of Reference document - this document provides a common understanding of the aims and objectives of The Alliance. It was agreed that RDSA will initially chair The Alliance, while the hosting of the meetings will rotate among the members.

The following founding objectives of The Alliance were agreed upon at the inaugural meeting of members:

1. Members will work together to:
  - 1.1 Act as the protectors and custodians for all those affected by rare diseases.
  - 1.2 Understand the existing gaps in services for rare diseases and collaboratively develop strategies to address such gaps and the causes of rare diseases.

- 1.3 Coordinate existing services and resources for rare diseases in Africa and ensure that these are equally and consistently applied.
  - 1.4 Ensure that existing resources and services are employed where needed, without misuse and to the benefit of patients and their family.
  - 1.5 Develop mechanisms for information-sharing in relation to trends, legislation, policies, data of incidence and service provision co-ordination.
2. The Alliance will be guided in its discussions and actions by the following principles:
- 2.1 To help to ensure that the rights of the patient and families are protected and underpinned by the provision made in legislation.
  - 2.2 To work together in a manner that seeks to understand and respect the values and areas of expertise of all those working with the Alliance.
  - 2.3 To adopt an ethos of collaboration, trust and respect within all members' dealings.
  - 2.4 To work with all stakeholders, whether members of the Alliance or not, for the betterment of children and their families diagnosed with rare diseases, by actively engaging and working with stakeholders on all levels of rare diseases regarding access to treatment and appropriate care.
  - 2.5 Members of the Alliance agree to, at all times, adhere to the African Alliance for Rare Diseases Code of Practice.

This document was drawn-up on from the inaugural meeting held on 20 October 2016 – At RareX, Spier Conference Centre, Cape Town, South Africa.