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MS M.P. MATSOSO, DIRECTOR-GENERAL OF HEALTH

RARE DISEASES CONFERENCE: 20 OCTOBER 2016

Thank you for inviting me to this important conference which is opportune. It takes place one year after the SDGS were adopted. Meaning we are left with 14 years to ensure no one is left behind. No one is left behind including those with rare diseases, neglected diseases even those living in countries that are still disproportionately affected by diseases of poverty.

UN Sustainable development goals are a universal call to end poverty, protect the environment and that people enjoy peace and prosperity. It is also about restoring dignity to the excluded.

In particular goal 3 is about ensuring healthy lives and promoting well being for all at all ages. The SDGS present an opportunity for us to advocate for positive change. For the goals to be achieved, there should be no one left behind. The furthest, the marginalised and the ignored, whoever and wherever they are. Unless we respond, the goals will not be reached and gaps will not be adequately addressed.

These apply to both rich and poor countries alike. It is about the principle of universality.

Rare diseases are a perfect example of a universal problem that afflict the poor and rich countries and thus require collective action.

Rare diseases are relevant because

1. They receive little attention and are thus ignored
2. They reflect failures in responding collectively
3. They demonstrate persistent obstacles to research, develop and supply diagnostics, medicines and related technologies to address neglected and rare diseases
4. Lack of market incentives and insufficient return on investment has shown to be the reason
5. However market based model has led to the development of life saving medicines, vaccines, diagnostics, medical devices but not shown to work where people are poor or the market is small
6. More needs to be done for Rare diseases and diseases that affect the poor, medicines for children because they are not young adults

We need:

- A. Mechanisms for coordinating, financing research and development of rare and neglected diseases.
- B. The same energy, effort and enthusiasm for the fight against Antimicrobial resistance should apply to Rare and neglected diseases.

- C. These mechanisms should complement existing innovative models
- D. We must explore innovative ideas on how to offset R&D costs in a sustainable way.
- E. The emergence of Product Development Partnerships provide useful lessons.
- F. These lessons can be explored for rare diseases
- G. Rare diseases are a medical challenge
- H. There must be an acceptable global definition
- I. There must be a collective effort to address them

Even though they are individually rare they are collectively common as you correctly state.

There must be a global action plan similar to AMR.