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Written statement at the 11th annual International Conference on Rare Diseases and Orphan Drugs

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Good morning, I send warm greetings to everyone gathered in Cape Town for the 11th ICORD meeting, the International Conference on Rare Diseases and Orphan Drugs. You are gathered over the next three days to discuss a matter of great importance to both health and international development communities. More than 300 million people around the world live with at least one rare disease. In most cases the nearly 7000 diseases which are classified as rare do not constitute a large enough market to incentivize much needed medical innovation. Where treatments do exist, they are often expensive, and place economic strain on individual patients and their families, as well as on health systems. Numerous studies from around the world, including studies by UNDP, show that ill health and the costs associated with it are major factors which push people into poverty. Thus the topic of this ICORD conference is as relevant to development practitioners as it is to health professionals.

There are many opportunities to address the specific issues faced by people living with rare diseases. Allow me to highlight three of these:

- The first is the 2030 Agenda for Sustainable Development which was adopted by UN Member States last year. At the heart of this new agenda and the seventeen Sustainable Development Goals which accompany it is a fundamental principle: “to leave no one behind”. The hard work has begun to transform this bold development agenda from words into actions at all levels – national, regional, and local – which will improve the lives and well-being of all. The 2030 Agenda is complex, and there is much to do, including on health. One of the key commitments under Goal 3, “ensuring healthy lives

for all”, is to achieve universal health coverage and provide “access to safe, effective, quality, and affordable essential medicines and vaccines for all”.

The research on and development of health technologies is an important element of universal health coverage. No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases.

- Second, the Report of the Secretary-General’s High-Level Panel on Access to Medicines was released last month. The report concluded that greater investments are required from governments to address the absence of adequate market incentives for unmet health needs such as rare diseases. UNDP is working closely with several governments to strengthen their legal and regulatory environments on health technology innovation and access. We welcome the opportunity to work more closely with ICORD in this regard.
- Third, sustainable development requires whole of government and society responses. Often the key obstacles to achieving an important goal will be outside the immediate sector targeted for attention. The several health-related targets outlined across the SDGs should serve as a reminder of how governments, civil society and patient groups, and industry and development partners can work together to increase access to health technologies within a relatively short time-frame. ICORD, as a multi-stakeholder society of patients, health professionals, researchers, regulators, health officials, and pharmaceutical industry representatives, offers a model of the collaboration which is needed to help achieve these important targets.

On behalf of UNDP, I wish you a productive and successful event at ICORD 2016, and thank you in advance for the work you will do in the coming days and years. Let us continue working toward inclusive and sustainable development for all, including for those with rare diseases.