Statement by the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Pūras, on the occasion of the inauguration of the NGO Committee for Rare Diseases at the United Nations

Geneva, 11 November 2016

It is a pleasure and an honor for me to address you in my capacity of the United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health on this very special occasion: the inauguration of the new NGO Committee for Rare Diseases at the United Nations. Unfortunately, I cannot be with you on this occasion but I would like to share with you some reflections about the importance of the theme you are discussing in this event and the right to health.

In my first report to the UN Human Rights Council in 2015, when I presented elements of my vision about the main challenges for the right to health and how they should be addressed globally and nationally, I highlighted the imbalances and power asymmetries that inform health – related policies. When these policies are formulated and, especially, when they are implemented, all too often important right to health issues are ignored or undermined when it comes to resources and political will. As these imbalances accumulate and are not properly addressed, they pave the way to serious gaps in health-related policies, and lead to violations of right to health, and other human rights.

History and evidence show that such imbalances and selective approaches reinforce the cycle of poverty, inequalities, social exclusion and discrimination, and are detrimental to the full enjoyment of the right to health. Moreover, inequalities and discrimination remain a crucial factor that hampers the full realization of the right to health as well as the healthy development of individuals and societies.

One of such examples of imbalances leading to discrimination and violations of right to health is the inadequate attention to persons affected by rare diseases, in particular when it comes to investments in health care services and research.

Factors leading to insufficient investments in research on rare diseases and inadequate coverage of expenses for the treatment of rare diseases are well known. What we need today is to raise awareness about it and mobilize the will of the main stakeholders globally, regionally and nationally, so that existing gaps in research are effectively closed, and discrimination against persons affected by rare diseases is put to an end.

The decision to launch an NGO Committee for Rare Diseases at the UN is very important and very timely. As you all know, health related issues are significantly present in Agenda 2030 for Sustainable Development, and they relate to many of the 17 Goals, not only to Goal 3. And when we speak about fundamental principle inspiring the SDGs, which is "leaving no one behind", we should apply this principle to those affected by rare diseases, children and adults.

An important key message from the UN stems from the Report of the Secretary General's High-Level Panel on Access to medicines, which was released not long ago. One of the conclusions of the Report is that greater investments are required to address the absence of adequate market incentives for unmet health needs, which applies to rare diseases.

I would like to emphasize the need to address the early identification and treatment of rare diseases, ideally during childhood. As we know, it is during childhood that many rare diseases occur, and we need to do our best to secure that these children affected enjoy their rights, equally with other children, to a dignified life, health, and holistic development. This is about non-dicrimination, justice, and equity of access to health care.

We, as a global community, need to learn our lessons. The Ebola crisis has starkly reminded us that we should not only react effectively to provide urgent international assistance and manage the consequences of such epidemic outbreaks. We also need to seriously analyze and address the root causes of outbreaks like this. And one of the root causes is generally the lack of capacity or will to implement rights-based approaches to health policies. Moreover, the Ebola crisis has reminded us of the insufficient attention paid by global institutions and actors to diseases of poverty and to neglected and rare diseases. Such gaps lead to dangerous imbalances and inequalities which carry a heavy price.

I wish all of you a productive and successful launch event of NGO Committee on Rare Diseases. I believe that the work of this Committee will be of utmost importance when it joins forces with all actors committed to make a difference in addressing the situation and promoting the rights of persons affected by rare diseases.

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