

Statement for Rare Diseases International Policy Event : The Right to Health: The Rare Disease Perspective, 10 February 2017

I envision a world in which everyone can lead healthy and productive lives, regardless of who they are or where they live. I believe the global commitment to sustainable development – enshrined in the Sustainable Development Goals – offers a unique opportunity to address the social, economic and political determinants of health and improve the health and wellbeing of people everywhere. “Health for All” must be the centre of gravity for efforts to achieve all of the SDGs – because when people are healthy, their families, communities and countries benefit. Yet today, too many people are left behind, with no access to quality healthcare. Among those who are overlooked are millions of people suffering from rare diseases.

With 300 - 350 million people affected worldwide, and more than 7,000 different types of diseases known to date, rare diseases represent a major challenge in public health that has been largely ignored. Consequently, this is a field in public health and research that would certainly benefit from globally concerted action and international collaboration. Better use of existing knowledge, as well as more resources to generate new data and knowledge, can greatly improve healthcare options for people living with rare diseases.

As a candidate for the position of Director-General of the World Health Organization (WHO), I believe WHO’s top priority must be to support national health authorities’ efforts to strengthen their core responsibilities – including health workforce, service delivery and health information systems – and to enact policies aimed at ensuring health coverage. Health coverage must include work in the area of rare diseases, and I would like to commend the leaders of the rare disease community for their commitment and determination evidenced through the launch of the NGO Committee for Rare Diseases at the United Nations in November of last year. The active involvement of civil society has been a key factor of success towards improving public health outcomes, and I know that this is the case in the fight against rare diseases where patient organisations are on the frontlines, promoting awareness, research, and access to funding.

Despite progress in research, only 5% of rare diseases have treatment options, which are often extremely expensive. On the occasion of the upcoming Rare Disease Day on February 28, I would like to especially highlight the vital importance of health-related research and development (R&D). Innovation is key if we are to meet the challenges posed by rare diseases. This is particularly true in areas where the market does not provide the incentives needed to develop new treatments. And too often we fail to appreciate the vital knock-on effects that research on rare and orphan diseases can have on treating more common diseases, serving as a model to help develop effective drugs on a larger scale. I believe we can reach more people with life-saving services by strengthening WHO’s normative authority and advocating to increase the availability and accessibility of effective, safe and affordable drugs, diagnostics and

vaccines where they are needed most. Through a global leadership role, WHO has the potential to greatly improve equitable access to health, moving the world closer to the achievement of the universal health coverage by, or before, 2030.

I hope that the policy event, organized by Rare Diseases International in cooperation with the BLACKSWAN Foundation and EURORDIS-Rare Diseases Europe, will pave the way towards a new paradigm for rare diseases. And I look forward to hearing the results of your discussions, and to working with you in the near future.

Tedros Adhanom Ghebreyesus, PhD

Minister, Special Advisor to the Prime Minister of Ethiopia