



The Global Gathering for Rare Diseases: Inaugurating the NGO Committee for Rare Diseases (CfRD)

Friday 11 November 2016, United Nations, New York

Context

The launch of the NGO Committee for Rare Diseases on Friday 11 November 2016 represents a historical moment for the global rare diseases community as it is the very first time ever that rare diseases will receive attention as a public health priority at the United Nations.

Rare diseases are a family of more than 6,000 medical conditions, each of which shares the common feature of affecting a small to very small population of patients – typically fewer than 1 in 2,000 individuals. As a whole, however, the burden of rare diseases is no less than that of other chronic diseases such as diabetes, with an estimated 350 million affected individuals worldwide. Many of these conditions are chronic, degenerative and disabling; and cut short life expectancy - 30% of patients living with a rare disease die before the age of 5.

The challenges of living with a rare disease are common across diseases and across geographies. To name but a few, they include: the scarcity of readily accessible information and medical expertise; the difficulty of obtaining an accurate diagnosis; the absence of treatment and care options; or the lack of funds and resources to encourage scientific research. In addition, the practical consequences reach far beyond the health niche, extending all the way to the socio-economic, family, education, labour and inclusion spheres.

The purpose of the NGO Committee for Rare Diseases shall be to bring visibility and understanding about rare diseases to the United Nations. By ensuring that no one person living with a rare disease is left behind, the Committee aims, in turn, to advance efforts to achieve the UN's Sustainable Development Goals in the areas of health and well-being; poverty; education; gender equality; inequalities; and partnerships.

Event Description

The launch of the NGO Committee for Rare Diseases shall take place on Friday 11 November 2016 at the United Nations Headquarters (Conference Room 8), in the form of an all-day conference (please refer to the programme enclosed separately). This global gathering will bring together around 90 to 100 stakeholders – from the international NGO community, UN agencies and national governments, academic and research institutions as well as the private sector – all

of whom will pledge to collaborate towards the advancement of rare diseases as a global public health priority.

This initial meeting shall represent the first opportunity for a genuine debate on the global state of play of rare diseases. It will also offer a platform for the presentation of the NGO Committee's Founding Act « Rare Diseases and the UN Sustainable Development Goals » and for a broad exchange of views on the Committee's forthcoming activities.

Main Partners

- The Conference of NGOs in Consultative Relationship with the United Nations (www.ngocongo.org)
- The Ågrenska Foundation (www.agrenska.se)
- EURORDIS-Rare Diseases Europe (www.eurordis.org)