

# RARE DISEASE DAY AT THE WORLD EXPO FOURTH HIGH-LEVEL MEETING OF THE NGO COMMITTEE FOR RARE DISEASES



A GLOBAL  
PRIORITY  
FOR EQUITY

## CONCEPT NOTE

**DATE:** Monday 28 February 2022

**TIME:** 10:30 – 16:30 GST / 07:30 – 13:30 CET

**WHERE:** Sweden Pavilion (Sustainability District), World Expo, Dubai (United Arab Emirates)

**CO-ORGANISERS:** NGO Committee for Rare Diseases with the support of the Swedish Government, and its co-founding organisations (Agrenska, Rare Diseases International and EURORDIS-Rare Diseases Europe).

**OVERVIEW:** Rare Disease Day was created in 2008 and aims to raise awareness with policy makers and the general public about rare diseases and their impact on the lives of the **300 million persons living with a rare disease (PLWRD) worldwide**. These individuals and their families experience vulnerability and are disproportionately affected by stigma, discrimination, and marginalization in all aspects of their lives. For them, knowledge and information are scarce, and expertise is not accessible. All of this leads to specific challenges in access to education, healthcare, employment, and leisure, and causes increased impoverishment and isolation. On top of that, the COVID-19 pandemic has worsened these socio-economic challenges. Therefore, **PLWRD require immediate and urgent attention**, under the auspices of innovative **global, regional, and national policies** that address their needs, respect their human rights, and lead to more inclusive, sustainable societies in line with the **UN Agenda 2030 and the Sustainable Development Goals**. Holding the fourth high-level meeting and celebrating Rare Disease Day 2022 at the Swedish Pavilion of the World Expo, which is dedicated to 'co-creation for innovation' within the Sustainability District, is perfectly aligned with this vision of the NGO Committee and its partners of moving towards equity, inclusion, and social justice for PLWRD and their families.

**OBJECTIVE OF THE EVENT:** The fourth high-level meeting of the NGO Committee for Rare Diseases held at the World Expo will be the opportunity to discuss how **key global intergovernmental commitments**, like the United Nations Political Declaration on Universal Health Coverage (UHC) and the recently adopted United Nations General Assembly Resolution on Addressing the Challenges of PLWRD and their families, **are key achievements to raise awareness and visibility, and must trickle down to the regional and national levels**. The all-day meeting will include multi-stakeholder panels exploring ways to increase international collaboration and synergies needed to make rare diseases a policy priority at all levels. In particular, it will focus on the African region, as it is increasingly emerging to the issue and fostering a favourable environment for the creation of pan-African networks in the field of rare diseases. Learnings from the panels, however, will go beyond Africa and explore roadmaps for rare diseases in low-and middleincome countries around the world.

**NGO COMMITTEE FOR RARE DISEASES:** This substantive committee, established under the umbrella of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO), aims to promote multi-stakeholder collaboration and actions for PLWRD within the UN System. Governance of the Committee is led by the current members of the Executive Board: grenska, EURORDIS-Rare Diseases Europe, Rare Diseases International, the International Alliance of Patients' Organizations, the International Alliance of Women, the International Federation for Spina Bifida and Hydrocephalus and the World Federation of Haemophilia, representing all their member organisations.

### ORGANISERS



### SUPPORTERS



### PARTNERS



### SPECIAL THANKS

