

NETWORKING EXPERTS, CENTERS OF EXPERTISE AND PATIENT ORGANIZATIONS TO STRENGTHEN HEALTH SYSTEMS FOR RARE DISEASES



24 May 2022 | 18:30 to 20:30 (CET)

CONCEPT NOTE

ORGANIZER: RARE DISEASES INTERNATIONAL (RDI)

OVERVIEW:

For the more than 300 million Persons Living with a Rare Disease (PLWRD) worldwide, the national healthcare system is the first point of contact in accessing healthcare. However, most national systems lack the resources necessary to adequately support PLWRD, starting with the absence of expertise to provide timely and accurate diagnosis. Indeed, the public health demands of rare diseases are documented, and it is recognized that no country alone can meet the multi-disciplinary needs of all rare diseases.[1],[2] Furthermore, the COVID-19 pandemic has additionally strained healthcare systems while aggravating the challenges of living with a rare disease.

Strengthening health systems for rare diseases represents a global equity priority. Indeed, it is key to fulfilling several international commitments including the 2030 Agenda and its Sustainable Development Goals, the Political Declaration on Universal Health Coverage (UHC), as well as the UN Resolution on “Addressing the challenges of persons living with a rare disease and their families” (UN RES 76/132), adopted by consensus in December 2021 by the UN General Assembly. The UN Resolution calls upon Member States to strengthen health systems in order to provide universal access to a wide range of healthcare services. [3]

Moreover, the World Health Organization’s 13th General Programme of Work 2019–2023 (GPW13) includes strengthening healthcare systems by fostering collaboration, aggregating expertise, and delivering a patient-centered approach to multidisciplinary care[4] as concrete steps toward UHC.

OBJECTIVE OF THE EVENT:

This informal side-event to the World Health Assembly aims to explore how national healthcare systems can be strengthened to better support PLWRD and help achieve existing international commitments. Participants will discuss how networking experts, centers of expertise, and patient organizations can help foster national and global “health systems strengthening”.

The event will present proposals for strengthening healthcare systems for PLWRD, with an in-depth look at the creation of a Global Rare Diseases Network. The event will start by sharing an operational description of rare diseases, followed by presenting and discussing five proposals on global networking to strengthen health systems. Finally, a panel of experts will detail, from different perspectives, the added-value of networking care globally, to establish a bottom-up approach in strengthening healthcare systems for rare diseases.

RARE DISEASES INTERNATIONAL (RDI): RDI is the global alliance of PLWRD and their families. RDI is a network of 82 organizations representing groups active in over 100 countries worldwide.

1.Hanna ER, Muzat C, Auquier P, Toumi M. Gene therapies development: slow progress and promising prospect. *J Mark Access Health Policy*, 2017; 5(1):1265293. doi:10.1080/20016689.2017.1265293.

2.Rath A, Salamon V, Peixoto S, Hivert V, Laville M, Segrestin B, Neugebauer EAM, Eikermann M, Bertele V, Garattini S, Wetterslev J, Banzi R, Jakobsen JC, Djuricic S, Kubiak C, Demotes-Mainard J, Gluud C. A systematic literature review of evidence-based clinical practice for rare diseases: what are the perceived and real barriers for improving the evidence and how can they be overcome? *Trials*, 2017 Nov 22; 18(1):556. doi: 10.1186/s13063-017-2287-7.

3. [United Nations General Assembly, Resolution on 'Addressing the challenges of persons living with a rare disease and their families'](#) (n.d).

4. People-Centred Care. Global Strategy