**Thought Leader Session, ECRD - Executive Summary**

**> Who were the participants, and how many?**

More than 140 participants joined the session. The participants included patient advocates, clinicians, researchers, industry partners, policy leaders, etc.

**> What were the main topics of discussion, challenges and opportunities mentioned?**

Rare Diseases International (RDI) is collaborating with the World Health Organization to develop a global “network of networks” that will connect existing collaborations of expert centres and patient organisations. The Global Network for Rare Diseases will support the implementation of Universal Health Coverage, targeting vulnerable and marginalised populations and progressively providing coverage, improving patient access and coordination of high-quality healthcare.

The session explored how healthcare systems in the WHO European region could connect into a Global Network for Rare Diseases, building on and scaling up the ERN system, exploiting the digitalisation of healthcare and harnessing the collective knowledge from the existing networks to unify an international expert community.

The main topics discussed the development of the ERNs and their international collaborations with the EMRO region. In particular, the session highlighted the partnership between the European Reference Network (ERN) [ERN eUROGEN](http://www.eurogen-ern.eu/) and [CureForU](http://www.cureforu.com/). This initiative supports virtual case reviews of infants with a rare urogenital disease in Pakistan, Afghanistan, and Uzbekistan. They need highly specialised surgery with experts from these countries connecting with experts from the ERNs.

The main challenges identified included securing funding to support the global network, e.g., seed funding for digital activities, support from regional and national authorities, grants, donations, and sponsorship. The session also highlighted the need to develop a sustainability strategy from the outset of the initiative.

**> What were the main conclusions made?**

The session reaffirmed the need for a Global Network for Rare Diseases. A network of networks in which clinical experts can offer their expertise anywhere in the world to help with the correct diagnosis and treatment plan and share learnings from the ground and technology from different countries. Each step in the rare disease community is a good step toward a global collaborative effort, as rare diseases are a global public health priority.

One insight gained was to leverage the tools, infrastructure and resources of existing networks and utilise the mature networks and collaborations to support the development of new networks and collaborations. For example, to explore how the ERNs can provide a learning and knowledge exchange space for other regions to learn from their experience setting up new EU networks.

The session highlighted the need for RDI to support local and regional communities to be able to apply to join the pilot network, which is expected to be organised in the coming year(s), for example: supporting the piloting of new regional hubs in low-and-middle-income countries and regions.

**> What are the next steps / key commitments?**

The UN Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their Families encourages Member States to foster the creation of networks of experts and multidisciplinary specialised expert hubs for rare diseases and to strengthen international collaboration on research and share data.

At the recent RDI Policy Event in Geneva, there was a call to action to bring the policymakers into the discussions, foster support from a Member State perspective and build on the European Commission's (EC) support. Dr. Krech, WHO highlighted that “now is the time to follow with actions… to strengthen health systems for rare diseases through the development of a global network on rare diseases.”

The next step is to explore with the EC and the ERN Coordinators Group the opportunities and activities that can now be undertaken to support the pilot network's development.