

STATEMENT
04 June 2024
Geneva, Switzerland

Rare Diseases International Admitted into Official Relations with WHO

Rare Diseases International (RDI) is pleased to announce that it was admitted into official relations with the World Health Organization at the 155th session of the WHO Executive Board held from 3-4 June in Geneva. This status gives RDI new opportunities to contribute expertise, insights and perspectives from the rare disease community to the development of policies and strategies within the WHO framework by increasing awareness on rare diseases and their visibility, identifying needs of the global rare disease community, and mapping available technical resources in rare diseases. It underscores the importance of raising the voices of those impacted by rare diseases and reinforces the principles of patient-centred healthcare within the global health agenda.

As the global alliance of rare disease organizations around the world, RDI is uniquely positioned to represent PLWRD at the WHO. The admission of RDI into official relations with the WHO builds upon a previous three-year collaboration and Memorandum of Understanding between RDI and the WHO and recognizes the important role that RDI plays in advocating for the rights of Persons Living with a Rare Disease (PLWRD) .

RDI's collaboration with WHO is framed within a three-year plan to support the WHO's strategic priority of ensuring that one billion more people benefit from universal health coverage through strengthening advocacy, awareness raising, sharing views from People Living with a Rare Disease (PLWRD), aligned with the Thirteen and Fourteenth General Programme of Work of WHO and providing technical input and expertise to WHO on rare diseases. RDI will continue to provide technical input and support to WHO's work on rare diseases and advocate for equitable access to essential health services for PLWRD.

RDI appreciates the support from the WHO and the Member States that worked conscientiously and collaboratively toward this very positive outcome, which reinforces the value of the Framework of Engagement with Non-State Actors (FENSA) process.

The official relations status will empower RDI to collaborate even more productively with the WHO and better assist Member States and the rare disease community in enhancing policies and initiatives for Persons Living with a Rare Disease and promote their access to healthcare and services at the global, regional and national levels. It will help strengthen the global response to rare diseases, enhance healthcare outcomes, and foster a more inclusive and equitable health landscape for all.