

[Press release]

Rare Diseases International, the global voice of rare disease patients, votes to become legally independent

"Alis volat propriis"

12 May 2018, Vienna – At the 2018 Rare Diseases International (RDI) Annual Meeting that took place in Vienna this week, members of RDI voted to become incorporated as a legally independent organisation.

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases. Since EURORDIS-Rare Diseases Europe and other national rare disease alliances launched RDI in 2015, the organisation has been independently governed by a council as a EURORDIS initiative. From now on, RDI is an independent organisation, separate from EURORDIS.

Under the EURORDIS umbrella, RDI has grown, over the last 3 years, to become a strong common voice on behalf of people living with a rare disease around the world.

EURORDIS' commitment to RDI and to rare disease patients around the world remains strong and will continue to grow thanks to a Memorandum of Understanding (MoU) signed by both organisations that sets out how they will work together over the next five years.

The organisation's mission is to be a strong common voice on behalf of rare disease patients around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities.

RDI works to make rare diseases a priority on the global health agenda, integrating rare diseases into the UN's Sustainable Development Goals and making rare diseases a priority within the UN system.

There are now [53 member organisations](#) – 30 national alliances of rare disease patient groups and 12 international disease-specific federations of patient groups, as well as 4 pan-regional networks, in turn representing rare disease patients in more than 100 countries.



Durhane Wong-Rieger, Chair of the RDI Council, and Yann Le Cam, Chief Executive Officer of EURORDIS, sign the MoU

Members of the RDI Council, as elected recently, are Angela Chaves ([Colombian Federation for Rare Diseases](#)), Ritu Jain ([DEBRA International](#)), Yann Le Cam ([EURORDIS-Rare Diseases Europe](#)), Lisa Phelps ([National Organization for Rare Disorders](#), US), Kin Ping Tsang ([Retina International](#)), Alfredo Toledo ([ALIBER](#)), and Chair of the RDI Council Durhane Wong-Rieger ([Canadian Organization for Rare Disorders](#)).

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EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 800 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit eurordis.org.

Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

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