Press release

EURORDIS-Rare Diseases Europe partners with EveryLife Foundation to support Brussels Rare Disease Week 2023

***23 January*, *Paris* – EURORDIS-Rare Diseases Europe is proud to announce a partnership with the EveryLife Foundation for Rare Diseases to launch the second annual Brussels Rare Disease Week, to raise awareness among EU policymakers of the high unmet needs of the 30 million people living with a rare disease in Europe.**

After a series of virtual meetings and training sessions that brought together more than 30 patient advocates as part of the first Rare Disease Week in 2021, EURORDIS will stage its first in-person iteration of the programme in Brussels from 6 to 9 February 2023.

Thanks to financial support from The EveryLife Foundation, EURORDIS will bring together 44 patient advocates from 21 countries to share the challenges of their rare disease journey with EU decision-makers. This is a unique opportunity for people living with rare disease to influence support for policies that can alleviate the physical, emotional and financial burdens of the 30 million Europeans living with a rare disease.

> "Rare disease is a global public health crisis and we are proud that patient advocacy efforts in Washington DC have helped enable EURORDIS to bring patients to meet with European Union policy makers," said Julia Jenkins, executive director of the EveryLife Foundation. "It's important that patients exercise their rights and raise their voices together to influence policies that can bring safe and effective treatments to rare disease patients quickly."

Throughout the week, the participants will meet with representatives of the Swedish EU Presidency, the European Commission, including Olga Solomon from DG Sante, and Members of the European Parliament, such as Frédérique Ries and Tilly Metz.

As part of the programme, EURORDIS will also convene a discussion on a patient-driven evolution of the Orphan Medicinal Product Regulation in the European Parliament on 8 February, gathering high-level decision-makers to address the vast unmet medical needs of the 20 million EU citizens living with a rare disease.

> "Isolation, exclusion, rejection. Unfortunately, these are often the words we hear from families affected by a rare disease. Thanks to cooperation between EURORDIS and the EveryLife Foundation, Rare Disease Week helps spark a conversation about rare diseases between patient advocates and policymakers and fosters solidarity and hope among the wider rare disease community. For better policies, better healthcare, and a better future for all," – added Yann Le Cam, Chief Executive Officer of EURORDIS-Rare Diseases Europe.

Inspired by EveryLife Foundation's Rare Disease Week on Capitol Hill, which is now in its 12th year, EURORDIS has organised Brussels Rare Disease Week since 2021 with the goal to empower rare disease patient advocates to participate effectively in advocacy activities at the European and national levels. Consequently, this would enable them to influence EU decision-making that has a direct impact on their lives.

Through Brussels Rare Disease Week, EURORDIS also works to raise awareness of rare diseases amongst EU decision-makers and present a strong and united message to MEPs and other policymakers in Brussels on behalf of the rare disease community.

About EveryLife Foundation

The EveryLife Foundation for Rare Diseases is a 501(c){3) non-profit, nonpartisan organisation dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.

About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 984 rare disease patient organisations from 74 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.

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The 30 million people living with a rare disease in Europe need to be heard. Brussels Rare Disease Week offers a unique opportunity to

Throughout the years, we have encouraged people living with a rare disease, their carers and families to be active participants in their own lives, to improve their experience and have better healthcare outcomes.