

Press Release

EURORDIS-Rare Diseases Europe Announces New Chief Executive Officer

15 December 2023, Paris – EURORDIS-Rare Diseases Europe proudly announces the appointment of Dr Virginie Bros-Facer (PhD) as its new Chief Executive Officer, starting March 2024. Virginie brings an extensive professional background in rare diseases, scientific research, and patient advocacy, combined with personal insights from her niece's experience with Congenital Disorders of Glycosylation.

"I am privileged to re-join EURORDIS as CEO. My goal will be to build on both my professional experience and personal insights in rare disease research and patient advocacy to further EURORDIS' mission, ensuring that the voices of all people living with a rare disease in Europe are heard and their needs are met," **Virginie stated.**



Yann Le Cam, outgoing Chief Executive Officer of EURORDIS, expressed his full confidence in Bros-Facer's leadership:

"I am thrilled to pass the baton to Virginie. Her unique blend of professional expertise and personal commitment to rare diseases makes her the ideal leader to guide EURORDIS into the future."

Avril Daly, President of EURORDIS, remarked:

"The EURORDIS Board of Directors is delighted to appoint Dr Virginie Bros-Facer as its new CEO after an open and highly competitive process, led by the EURORDIS Board of Directors. We are confident that her commitment to all people living with rare diseases, which is rooted in lived experience, will underpin her leadership in advocating for the 30 million Europeans living with rare diseases. Her vision for the organisation includes strengthening collaborations with member organisations, working with our Council of National Alliances and Council of European Federations, enhancing patient engagement, and amplifying the voice of people with rare diseases in policy discussions at both European and global levels."



###

About Dr Virginie Bros-Facer (PhD)

Virginie Bros-Facer received her PhD in Neurosciences from King's College London, UK, followed by several postdoctoral research projects at the Institute of Neurology, UCL, London, focused on testing therapeutic strategies for Amyotrophic Lateral Sclerosis.

After leaving the lab, she worked for several research funding organisations in the UK, including the National Institute for Health Research, the Medical Research Council, and as Medical Director for Sparks, a medical research charity focusing on rare paediatric diseases.

Virginie then joined EURORDIS-Rare Diseases Europe as Scientific Director, where she led on project development and patient engagement in rare disease research projects, representing the voice of rare disease patients, including within the International Rare Disease Research Consortium (IRDiRC). Virginie spearheaded the creation of the EURORDIS Winter School on Scientific Innovation and Translational Research, to empower people living with rare diseases (PLWRD) to fight for their rights to a better and healthier future.

Just under two years ago, Virginie joined Illumina as Associate Director for Medical Affairs, Europe, where she is engaging key opinion leaders and centres of excellence to develop clinical evidence for genetic testing of rare and undiagnosed patients, to drive clinical NGS adoption and implementation in patient care.

She has rejoined IRDiRC as a member of the Diagnostic Scientific Committee and coordinates a dedicated working group on real-world applications and technologies for newborn screening.

Contact

Stanislav Ostapenko
Senior Communications Manager
EURORDIS-Rare Diseases Europe
stanislav.ostapenko@eurordis.org
+33 7 88 94 90 31

EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1000 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.