

Press release

Virginie Hivert, Therapeutic Development Director at EURORDIS, appointed to the Management Board of European Medicines Agency

16 June 2022, Paris - Virginie Hivert, PharmD, PhD, Therapeutic Development Director at EURORDIS-Rare Diseases Europe, has been appointed to the Management Board of the European Medicines Agency (EMA) as a civil society representative. The EMA Board is made up of representatives of each of the 27 EU Member States, the European Commission, the European Parliament, two civil society organisations, and doctor and veterinarian organisations.

This is an extremely important milestone for the rare disease community in recognition of EURORDIS' leadership and awareness over the past 25 years. The appointment of Virginie ensures that the patient voice is present at the European Medicines Agency to enhance dialogue with all stakeholders. The rare disease community is at a turning point with the rise of advanced therapies and the surge of precision medicine which makes her nomination even more timely.

"It is a privilege to be appointed to the EMA Management Board and it comes with a huge sense of responsibility to represent civil society. I see my role as helping the European Medicines Agency to fulfil its public health mission that is to ensure the quality, efficacy, and safety of medicines. This is while embracing scientific innovation and new opportunities and challenges of society's digitalisation, which is especially pertinent for people living with a rare disease, as well as driving Europe's responsiveness to future public health emergencies."

– Virginie Hivert, PharmD, PhD, EURORDIS Therapeutic Development Director

Virginie draws on experience from many years at the European Medicines Agency, as an observer on the Committee for Orphan Medicinal Products (COMP) for 7 years and as the alternate member representing patients' organisations on the Pharmacovigilance and Risk Assessment Committee (PRAC) during the past mandate. During this time, she coordinated the group of high-level rare disease representatives, members of scientific committees and working parties at the EMA, also known as the EURORDIS Therapeutic Action Group (TAG).

Prior to joining EURORDIS in 2014, Virginie had gathered extensive knowledge on rare diseases when working at Orphanet, a rare disease and orphan drugs' database. At that time, she started to be involved with the International Rare Diseases Research Consortium (IRDiRC) and in particular with its Therapies Scientific Committee which she co-chaired from 2017 to 2021.

Newly appointed members of the EMA Management Board are: Mr Marco Greco and Ms Virginie Hivert (patient organisations); Mr Denis Lacombe (doctors' organisations); Ms Despoina Iatridou (veterinarians' organisations).

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 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. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit [eurordis.org](#).

Press contact

Stanislav Ostapenko
Communications Senior Manager
EURORDIS-Rare Diseases Europe
stanislav.ostapenko@eurordis.org
+33 1 56 53 52 61