Yann Le Cam appointed to Board of the European Medicines Agency

Yann Le Cam, Chief Executive Officer of EURORDIS, was recently appointed to the Management Board of the European Medicines Agency (EMA). Here he explains that his appointment is a tribute to the entire rare disease and patient community.

The EMA Board is made up of representatives of each of the 28 EU Member States, the European Commission, the European Parliament, two civil society organisations, and doctor and veterinarian organisations.

You have been a patient advocate for over 25 years. Since co-founding EURORDIS in 1997 and becoming Chief Executive Officer of the organisation in 2000, you have relentlessly represented the rare disease patient voice at the EMA, the European Commission, in conversation with industry and medicines regulators, and throughout all of EURORDIS' activity.

Why is this appointment important to you?

I am delighted to have been appointed to the EMA Board. This is not a personal win. This is a victory for the rare disease community. After 20 years of campaigning to raise awareness of rare diseases in Europe, orphan medicines, other rare disease therapies and paediatric medicines represent a large proportion of new medicines approved each year. We are also recognised for our leadership to shape agendas and promote innovative approaches.

What experience do you bring to the role of Board member?

I bring my experience as an authentic patient representative. I have previous personal experience of being a patient representative at the EMA from my 9 years as a patient representative on the Committee for Orphan Medicinal Products and as its elected vice-chair for two mandates.

Through my previous appointments in management of public institutions, I have also had the opportunity to gain a broad expertise in research and development of medicines and how to ensure this process is focused on improving patient health outcomes, while also taking on board the concerns of other various stakeholders.

What do you hope to achieve in your position on the EMA Board?

I hope to use my experience to enhance dialogue with all stakeholders (patient organisations, the European Commission, Members of the European Parliament, industry etc.) with a focus on the product life cycle and particular attention to patient access. I look forward to providing input on EMA relations with patient organisations, participation of patient representatives as members or experts of EMA committees and working parties, and participation of patient representatives in EMA risk/benefit assessment.

I will also bring the patient perspective to debates on how the EMA can respond to emerging opportunities on precision medicine, data collection, e-health, registries, and healthcare systems to support progressive patient access (for example the PRIME scheme), among other issues.

How is EURORDIS already involved with EMA activity?

EURORDIS has played a pioneering role in ensuring the patient voice is present at the EMA. We support the presence of patient advocates on numerous EMA committees (including the Committee for Orphan Medicinal Products, Committee for Advanced Therapies and the Paediatric Committee), in protocol assistance programmes, the Scientific Advice Working Party and beyond. EURORDIS is also a member of the Patients' and Consumers' Working Party.

Eva Bearryman, Junior Communications Manager, EURORDIS

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