

Le Cam, Yann

EURORDIS-Rare Diseases Europe



Yann was one of the founders of EURORDIS-Rare Diseases Europe in 1997. He is the organisation's Chief Executive Officer since 2000.

Yann initiated Rare Diseases International (RDI) in 2009. He is an elected member of the RDI Council and Chair of the RDI Advocacy Committee. He is a founding member of the NGO Committee for Rare Diseases (United Nations, New York) in 2014 and its Vice-Chair. Yann is a Co-Chair of the Global Commission to End the Diagnostic Odyssey of Children with Rare Diseases since its launch in 2018. Yann is a member of the World Economic Forum's Health Stewards Board from 2020 and of its Global Precision Medicine Council since 2019.

Recent past positions include: member of the Management Board of the European Medicines Agency (EMA) 2017-2019; Chair of the Therapies Scientific Committee of the International Rare Diseases Research Consortium (IRDiRC), 2013-2017; Vice-Chairman of the EU Committee of Experts on Rare Diseases (EUCERD), 2011 – 2013; and a member of the Commission Expert Group on Rare Diseases, 2014 – 2017; member of the Committee for Orphan Medicinal Products (COMP) at the EMA, served 9 years, two elected mandate as vice-chair for 6 years.

Yann holds an MBA from HEC Paris. He has three daughters, the eldest of whom is living with cystic fibrosis.