

Domenica Taruscio, MD, PhD, graduated at the University Alma Mater Studiorum (Bologna, Italy), holds a specialization in Histopathology (University of Bologna), a master in Bioethics (University Sapienza, Rome). She has carried out her post-doctoral studies in Human Genetics at Yale University (CT-USA) (1989-1991).

Director of the National Center for Rare Diseases at the National Institute of Health (Istituto Superiore di Sanità, Rome) (2008 – up to now).

Dr Taruscio is an active contributor to the development of the European scientific and institutional framework on rare diseases. Her studies have been directed on rare diseases: from prevention through to diagnosis and care of patients, training of health professionals, information to citizens and empowerment of patients and improvement of their quality of life. Her activity pivots on the cross-talk between science and society.

Member of the Committee for Orphan Medicinal Products - COMP at EMA (2000-2009). Since 2004 member of: the former European Rare Diseases Task Force; European Union Committee of Experts on Rare Diseases (EUCERD); European Commission Experts Group on Rare Diseases. Member of the “Health Research” Advisory Group (EC, DG Research). Member of Advisory Board of the European Molecular Genetics Quality Network (EMQN).

She coordinated or participated to several projects funded by the European Commission. She is member of national, european and international committees, including the International Rare Diseases Research Consortium (IRDiRC, <https://irdirc.org>). She represents Italy at the European Commission in the Board of Member States for the European Reference Networks (2019- up to now).

Past President (2010-2012) and President (2021-2023) of ICORD (<http://icord.es>) the International Society whose mission is to improve the welfare of patients with rare diseases and their families world-wide through better knowledge, research, care, information, education and awareness. Charter member of the UDNI ([www.udni.org](http://www.udni.org)) (2014 - up to now); co-chair of UDNI Developing Nations Working Group (2020 - up to now), member of the Education Committee of the UDNI. Member of the Multidisciplinary Joint Committee of the Rare and Undiagnosed Diseases (MJC RUD) of the UEMS.

In July 2021 she has been nominated Member of the Academia de Ciencias Medicas (Corboda, Argentina) and Member of the Facultad de Ciencias Medicas (Universidad National de Corboba, Argentina). Dr. Taruscio has co-authored over 200 peer-reviewed research articles and book chapters.