

Domenica Taruscio

Domenica Taruscio, Director of the National Centre for Rare Diseases (www.iss.it/cnmr), at the Italian National Institute of Health, Rome (Italy). For decades, her efforts have been mainly directed to face the many and complex challenges posed by rare diseases. She has addressed them from various facets from science to society; she authored more than 100 indexed scientific papers, in addition to many international reports and book chapters.

Scientific coordinator of European and International projects on rare diseases, e.g. EUROPLAN (www.europlanproject.eu), EPIRARE (www.epirare.eu/); RARE-Bestpractices (www.rarebestpractices.eu); co-ordinator of the following Work-packages: "Registries" in RD-Connect (www.rd-connect.eu); "Rare Diseases" in ADVANCE-HTA (www.advance-hta.eu); E-RARE (www.erare.eu); co-coordinator of "Rare and undiagnosed diseases - a bilateral USA-Italy project (2016-2018).

Member at the Committee for Orphan Medicinal Products-EMA (2000-2009); Expert Member at European Commission Experts Group on Rare Diseases (2004 up to date); Expert Member European Commission "Health Research" Advisory Group (2010-2013); Member of the Interdisciplinary Committee and co-chair of the Working Group "Registries and natural history" in IRDiRC (www.irdirc.org). Past-President of ICORD (www.icord.se).

Director of the International Summer School "Registries for rare diseases" and International Courses on RARE-Bestpractices.