

**3rd International Summer School on
Rare Disease and Orphan Drug Registries**

September 21-23, 2015

and

RD-Connect Workshop Data linkage and ontologies

September 24-25, 2015

*National Centre for Rare Diseases
Istituto Superiore di Sanità
Viale Regina Elena 299, Rome (Italy)*

ANNOUNCEMENT and CALL FOR REGISTRATION

The two events intend to promote the development of rare disease registries complying with the IRDiRC (www.irdirc.org) and EU Recommendations (http://ec.europa.eu/health/rare_diseases/policy/index_en.htm), and to support cooperation among different registry stakeholders (www.epirare.eu; <http://rd-connect.eu>), and coordination with registries developed within national plans in the EU in the field of rare diseases (www.euoplanproject.eu).

This initiative is endorsed by ICORD (<http://icord.se>).

This year the program of the International Summer School will be focused on the specific aims and needs of registries oriented to clinical research, comprising the study of the natural history of diseases, the assessment of treatment effectiveness and post-marketing surveillance of orphan drugs.

The School will train participants on the methodologies and resources available for the establishment of a clinical research registry and on the implementation of successful strategies to ensure long time sustainability of the registry, including data sharing and dissemination activities.

The RD-Connect (<http://rd-connect.eu>) workshop will allow attendants to learn new concepts and tools for applying ontologies to their data and make them interoperable with other data coming from different sources.

The School will consist of frontal presentations followed by interactive small-group exercises on relevant registry cases.

The Workshop will consist of brief frontal presentations and practical working groups where participants will learn to make their data interoperable with other sources and databases. The working groups will get together registry owners and bio-informatics experts.

The two events are open to health professionals, researchers, medical specialists, medical students and representatives of patient associations, who are involved or intend to establish a rare disease patient registry. A selection process will apply based on the participant's background and role with reference to registry activities.

Fees and costs: Registration is free of charge. The School does not cover any travel, subsistence and other costs incurred by the participants to attend the School.

Registration is carried out by filling the on-line form at http://it.surveymonkey.com/s/Summer_School_2015

Registration can be carried out for either one or both events.

Important dates

Final Program: the Final Program of the International Summer School and of the Workshop will be published within **May 29, 2015**.

Deadline for registration: July 20, 2015. Due to organizational constraints, registration after this date cannot not be guaranteed.

Notification of acceptance: July 24, 2015.

Registered participants will be informed by e-mail. For additional information, clarifications, or questions, please contact the School secretariat at rareregistries-school@iss.it

Best Regards.
Domenica Taruscio

Dr. Domenica Taruscio
Director
National Centre for Rare Diseases
Istituto Superiore di Sanità
Rome (Italy)