



4th ES AI HF PO

SYNERGY
CERTIFICATION
COURSE

Rare diseases
and orphan
medicines
as an integral
part
of European
healthcare
setting



11-12 May 2023

Acquario romano Rome
Rome, Italy

4th EAHP SIFO Synergy Certification Course Rare diseases and orphan medicines as an integral part of European healthcare setting

Acquario Romano
Piazza Manfredo Fanti, 47, Rome
May 11-12, 2023

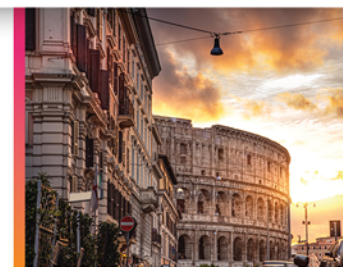
Rationale

Rare diseases are defined by the European Union as life-threatening or chronically debilitating conditions with a prevalence lower than 4 per 10 000 inhabitants. Around 6000 diseases are described, affecting between 6% and 8% of the European population. Due to the severity and the distribution of rare diseases across Europe, its multifaceted nature and accompanying economic challenges, it is important to improve the knowledge and the awareness of rare diseases among healthcare professionals and patients. Moreover, since a multidisciplinary healthcare professionals' approach is needed to manage rare diseases, it is crucial to improve their collaboration and perception of various aspects and specificity of their management.

During this EAHP Synergy Certification Course the attendees will be able to acquire more knowledge about:

- European policies on rare diseases and health insurance funds management.
- Access to and approval of new medicines according to the EMA perspective.
- The management and the therapeutic pathways for rare diseases; the relevance of the rare disease's networks and the role of genetics in rare diseases.
- The patient perspectives and the available patient support programmes in Europe related to rare diseases.
- The role of the Real World Evidence (RWE) in the evaluation of rare diseases.
- The sustainability of innovative treatments for rare diseases in the context of overall public health care system.
- The complexity of dispensing orphan medicines or medical devices for patients affected by rare diseases according to the experience of the hospital pharmacist.
- The effective communication on rare diseases across healthcare sectors and with patients.
- Available databases, observatories and websites with useful information on rare diseases and orphan medicines.

An interactive panel discussion will facilitate exchange and interaction among synergy certification course participants and the speakers coming across Europe.



Program
Day 1, May 11th 2023

The European Regulatory Framework

15.00-15.10 Invitational speech by the organizers, Italian Society of Hospital Pharmacists (SIFO) and European Association of Hospital Pharmacists (EAHP) - *Arturo Cavaliere President of SIFO and Andras Sule President of EAHP*

15.10-15.15 Welcome – needs and objectives of the 4th EAHP Synergy Certification Course-Day 1 - *Piera Polidori, EAHP Director of Professional Development and Nenad Miljković, EAHP Director of Finance*

15.15-15.20 Moderators

Marcello Pani and Francesco Cattel

15.20-15.50 European policies on rare diseases and health insurance funds managements - *Mr Istvan Ujhelyi and Dr Tomislav Sokol - MEP- European parliament*

15.50-16.30 Management and therapeutic pathways for rare disease: comparison between regions - *Giuseppe Limongelli Responsible of the Coordination Center for Rare Disease Campania Region; Maurizio Scarpa Responsible of the Coordination Center for Rare Disease Friuli Venezia Giulia Region*

16.30-16.45 *Coffee break*

16.45-17.00 European patients' perspectives on rare diseases - *Simone Boselli, EURORDIS Public affair director*

17.00-17.15 Access to orphan drugs - *Niklas Hedberg, co-chair of the new HTA Coordination Group* **TBC**

17.15-17.35 Example of rare diseases the experience of the Gemelli hospital – Rome - *Stanislao Rizzo*

17.35-17.50 Interactive panel discussion

17.50-18.00 Summary – End of Day 1



Day 2, May 12nd 2023

Organization of healthcare teams for the treatment of rare diseases

Moderators: Barbara Meini and Carlo Polidori

- 09.00-09.10 Welcome – needs and objectives of the 4th EAHP Synergy Certification Course- Day 2 -
Barbara Meini and Carlo Polidori (moderators)
- 09.10-09.30 Effective communication in Rare Diseases – *Daniela Scala*
- 09.30-10.00 Patient support programs in Europe - *Jacopo Koch, CEO Healthcare Network Partners Italy Spa*
- 10.00-11.00 Genetics in rare diseases – *Maria Piccione, Emanuela Salzano, AOOR Villa Sofia Cervello Hospitals Palermo*
- 11.00-11.20 *Coffee break*
- 11.20-11.45 The role of the RWE in the evaluation of rare diseases - *Gianluca Trifirò, Department of Diagnostics and Public Health, University of Verona, Italy*
- 11.45-12.10 The sustainability of innovation for rare diseases in the context of public health - *Federico Spadonaro and Barbara Polistena, Università di Roma San Raffaele, C.R.E.A. Sanità*
- 12.10-12.30 Interactive panel discussion
- 12.30-14.00 *Lunch*
- From theory to practice**
- Moderators: Alessandro D'Arpino and Maria Ernestina Faggiano**
- 14.00-14.30 Complexity of dispensing of orphan drugs or medical devices for patients affected by rare diseases - *Maurizio Pastorello, Italy*
- 15.00-15.15 Omar: communication at the service of rare disease- *Ilaria Ciancaleoni Bartoli, Direttore Omar (Italian observatory of rare diseases)*



15.15-15.30 Orphanet: a database at the service of rare diseases - *Dr. Michele Nutini Senior Information Scientist- Orphanet Italy*

15.30-16.00 Take home message- illustration of survey data and take home messages - *Piera Polidori, EAHP Director of Professional Development and Nenad Miljković, EAHP Director of Finance*

Scientific Committee

Piera Polidori, EAHP Director of Professional Development

Nenad Miljković, EAHP Director of Finance

Maria Ernestina Faggiano, SIFO Director of Finance

Congress Venue

Acquario Romano

Piazza Manfredo Fanti, 47

Rome

REGISTRATION FEES

- ✓ SIFO member and EAHP member states pharmacists in good standing (membership fee for 2023 paid): 183,00 € (150€ + applicable VAT 22%)
- ✓ Pharmacists non member: 305,00 € (250€ + applicable VAT 22%)

REGISTRATION INCLUDES:

- Access to the conference sessions
- Coffee Breaks
- Lunch
- Certificate of attendance
- CME accreditation
- VAT

SIFO Scientific Secretariat

(Provider Standard Nazionale ID n. 313)
Via C. Farini, 81 • 20159 Milano
tel. 026071934 • fax 0269002476
info@sifo.it • www.sifoweb.it

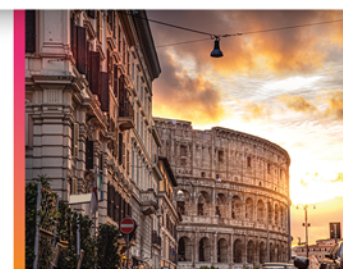
EAHP Scientific Secretariat

Boulevard Brand Whitlock 87
Box 11 (4th floor) 1200 Brussels
Tel: +32 (0) 2/669.25.15 • Fax: +32 (0) 2/669.25.29
<https://www.eahp.eu/>

Organizing Secretariat



Planning Congressi
Via Guelfa 9 • 40138 Bologna (Italy)
T. +39 051 300100 (dir. 051 6037960)
Email: r.cantelli@planning.it • www.planning.it



Rare diseases and orphan medicines
as an integral part of European
healthcare setting

11-12 May 2023
Acquario romano Rome
Rome, Italy

SIFO scientific secretariat

(Provider Standard Nazionale ID n. 313)
Via C. Farini, 81 - 20159 Milano
Tel.: +39 026071934 – Fax: +39
0269002476
info@sifo.it – www.sifoweb.it

Organizing Secretariat

PLANNING Congressi Srl
Via Guelfa, 9
40138 Bologna (Italy)
Tel.: +39 051 300100
r.cantelli@planning.it

EAHP scientific secretariat

Boulevard Brand Whitlock 87
Box 11 (4th floor) 1200 Brussels
Tel.: +32 (0) 2/669.25.15 - Fax: +32 (0)
2/669.25.29
<https://www.eahp.eu/>

