



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.

SIFO Scientific Secretariat

(Provider Standard Nazionale ID n. 313)
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EAHP Scientific Secretariat

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Organizing Secretariat



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Program

Program “The European Regulatory Framework”

Day 1, May 11th 2023

- 15.00-15.10 Invitational speech by the organizers, Italian Society of Hospital Pharmacists (SIFO) and European Association of Hospital Pharmacists (EAHP)
Arturo Cavaliere, Andras Sule
- 15.10-15.15 Welcome – needs and objectives of the 4th EAHP Synergy Certification Course-Day 1
Piera Polidori, Nenad Miljković
- 15.15-15.20 **Moderators: Marcello Pani and Maria Ernestina Faggiano**
- 15.20-15.50 European policies on rare diseases and health insurance funds managements
Istvan Ujhelyi, Tomislav Sokol – remote connection
- 15.50-16.30 Management and therapeutic pathways for rare disease: comparison between regions
Giuseppe Limongelli, Maurizio Scarpa
- 16.30-16.45 *Coffee break*
- 16.45-17.00 European patients’ perspectives on rare diseases
Simone Boselli
- 17.00-17.15 Access to orphan drugs
Armando Magrelli
- 17.15-17.35 Example of rare diseases the experience of the Gemelli hospital – Rome
Stanislao Rizzo
- 17.35-17.50 Interactive panel discussion
Session Speakers
- 17.50-18.00 Summary – End of Day 1
Piera Polidori, Nenad Miljković

18.00-19.00 *Cocktail*



Program "Organization of healthcare teams for the treatment of rare diseases"

Day 2, May 12th 2023

Moderators: Alessandro D'Arpino and Carlo Polidori

09.00-09.10 Welcome – needs and objectives of the 4th EAHP Synergy Certification Course- Day 2
Alessandro D'Arpino, Carlo Polidori

09.10-09.30 Effective communication in Rare Diseases
Daniela Scala

09.30-10.00 Patient support programs in Europe
Jacobs Koch

10.00-11.00 Genetics in rare diseases
Maria Piccione, Emanuela Salzano

11.00-11.20 *Coffee break*

11.20-11.45 The role of the RWE in the evaluation of rare diseases
Gianluca Trifirò

11.45-12.10 The sustainability of innovation for rare diseases in the context of public health
Federico Spandonaro, Barbara Polistena

12.10-12.30 Interactive panel discussion
Session Speakers

12.30-14.00 *Lunch*

Program "From theory to practice"

Day 2, May 12th 2023

Moderators: Barbara Meini and Francesco Cattell

14.00-14.30 Complexity of dispensing of orphan drugs or medical devices for patients affected by rare diseases
Maurizio Pastorello

15.00-15.15 Omar: communication at the service of rare disease
Ilaria Ciancaleoni Bartoli



- 15.15-15.30 Orphanet: a database at the service of rare diseases
Michele Nutini
- 15.30-15.45 The Key role of Patient's Associations in early access and evaluations of therapies
Annalisa Scopinaro
- 15.45-16.00 Take home message- illustration of survey data and take-home messages
Piera Polidori, Nenad Miljković

Project Chief Scientific and Scientific Committee

- Dott.ssa P. Polidori** - SIFO Head of Delegation EAHP - SIFO Board of Auditors (President)
Dott. N. Miljkovic – Serbia EAHP Director of Finance
Dott.ssa M.E. Faggiano - SIFO Board of Directors (Treasurer) - National University Referent

Faculty

BOSELLI Simone

Director of Public Affairs Director of Public Affairs EURORDIS

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SIFO HTA Laboratory Coordinator
Hospital Pharmacy Director - AOU City of Health and Science of Turin

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Director of Pharmacy multispecialty department, ASL Viterbo Lazio Region

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Pharmacist Director - Hospital Pharmacy, University Hospital of Perugia

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Executive Pharmacist, Pharmacy Service, AOU Consortium Polyclinic of Bari

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KOCH Jacobs

CEO Healthcare Network Partners Italy Spa

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Vice-Chair of Committee Orphan Medicinal Products, European Medicine Agency

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Serbia EAHP Director of Finance

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Senior Information Scientist- Orphanet Italy

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SIFO Board of Directors (SIFO National Secretary)
Director of Pharmacy multispecialty department A. Gemelli University Hospital

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Director of the Pharmacy multispecialty department; Director of the Pharmaceutical Department

PICCIONE Maria

Specialist center coordinator – Orphanet

POLIDORI Carlo

Member of the Single Scientific Committee for Research and Training SIFO
Professor in Pharmacology School of Pharmaceutical Sciences and Health Products, University of Pharmacy of Camerino (MC)

POLIDORI Piera

SIFO Head of Delegation EAHP - SIFO Board of Auditors (President)
Director of the Pharmacy unit of the Villa Sofia-Cervello hospitals

POLISTENA Barbara

Researcher at the University of Rome "Tor Vergata" and collaborator of C.R.E.A. Sanità

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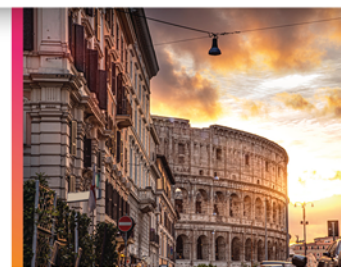
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Full Professor MED/30 OPHTHALMOLOGY Sacro Cuore Catholic University -Rome

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Pediatric Geneticist at Regional Referral Centre for Rare Genetic and Chromosomal Diseases

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Coordinator ASC SIFO Scientific Information, Counseling and Narrative Pharmacy
Pharmacist Manager I level UOSD Nuclear Medicine Hospital "A. Cardarelli"

SCARPA Maurizio

Director SOC Regional Reference Center for Rare Diseases

SCOPINARO Annalisa

President of UNIAMO - Italian Federation of Rare Diseases

SOKOL Tomislav – remote connection

MEP - European parliament

SPANDONARO Federico

Department of Economy - Telematic University San Raffaele Rome
President of the Scientific Committee of C.R.E.A. Sanità (Centre for Applied Economic Research in Healthcare)

SULE Andras

President EAHP - Chief Pharmacist of Péterfy Hospital and Trauma Center e Chief Pharmacy Advisor for Duna Medical Center

TRIFIRÒ Gianluca

Professor Department of Diagnostics and Public Health, University of Verona, Italy

UJHELYI Istvan – remote connection

Members of the European Parliament, Group of the Progressive Alliance of Socialists and Democrats in the European Parliament

GENERAL INFORMATION

Congress Venue

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Rome

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Target: n. 150 Pharmacist

CME: The event is included in the SIFO Annual Plan 2023 for the profession of Pharmacist. SIFO (Italian Provider ID 313) has assigned event n. **5,6 credits CME** (Continuing Medical Education). Please note that the release of the credit certification is subject to the participation of at least 90% of the duration of the work, the passing of the learning test and the completion of the evaluation form of the event.

National Objective: n. 18 - contenuti tecnico-professionali (conoscenze e competenze) specifici di ciascuna professione, di ciascuna specializzazione e di ciascuna attività ultraspecialistica, ivi incluse le malattie rare e la medicina di genere

Training duration: 8 hours

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

On-line registration: <https://webplatform.planning.it/EAHP2023/register>

Registration will be open until May 8, 2023

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