



# Training for patient representatives and advocates on leadership and communication skills

**November 10 - 11, 2022**

**Istituto Superiore di Sanità, Rome, Italy**



This Training has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No 825575 - European Joint Programme on Rare Diseases

## GENERAL INFORMATION

10<sup>th</sup> – 11<sup>th</sup> November 2022.

**The training course will be held in an ONLINE FORMAT, given the uncertainties linked to the evolution of the Covid-19 pandemic and to the international situation.**

REGISTRATION is now open for the RESERVE LIST only at this [LINK](#) until the 29<sup>th</sup> of May 2022.

The selected participants will receive an email by the 3<sup>rd</sup> of May. The non-selected participants should consider themselves on a reserve list until the 3<sup>rd</sup> of October.

All applicants will receive an email on the status of their application (if accepted, in reserve list or not accepted) by the 3<sup>rd</sup> of October 2022.

### RELEVANCE, INTRODUCTION AND OBJECTIVES

The International Course “Training for patient representatives and advocates on leadership and communication skills” is part of a series of training activities proposed by the EJP RD. EJP RD is a European Commission funded project (Grant Agreement 825575, 2019 – 2023) with the goal to create a comprehensive sustainable ecosystem, allowing a virtuous circle between research, care and medical innovation.

This International course is part of Work Package 15 of the EJP RD, “Capacity building and training of patients and researchers in Rare Disease research and process”, Task 15.3 “Training for patient representatives and advocates on leadership and communication skills”. WP and Task Leader: [EURORDIS](#) -Rare Disease Europe, France.

Course Director (Ed. 2022): Dr Claudio Carta, ISS.

The Course is a 2 days training preceded by webinars. The edition of 2022 is organised by [ISS](#), Istituto Superiore di Sanità, in close collaboration with WP15 and Task Leader [EURORDIS](#) -Rare Disease Europe, France, and the other EJP RD task partners: [ACU/ACURARE](#)–Acibadem Universitesi, Istanbul, Turkey, and [MUG](#) -The Medical University of Gdańsk.

In collaboration with [UNIAMO](#) Federazione Italiana Malattie Rare.

DRAFT



This Training has received funding from the European Union’s Horizon 2020 Research and Innovation Programme under Grant Agreement No 825575 - European Joint Programme on Rare Diseases

The course aims to teach participants presentation, negotiation and leadership skills, through plenary presentations and role-playing sessions, in order to improve their ability to communicate and represent needs in an assertive way, to influence important decisions and to guide the strategic decision-making, when engaging with healthcare providers and other rare disease stakeholders. The course will moreover promote basic knowledge on networks, healthcare pathways, integrated care, e-health, research, therapeutic development and knowledge generation.

## **SPECIFIC LEARNING OBJECTIVES**

At the end of the training course, participants will be able to:

1. Enunciate the elements that distinguish a good communicator
2. Communicate in an assertive way (following the acquired key-factors)
3. Outline the characteristics of an effective leadership
4. List conflict resolution strategies
5. Summarise the elements of an authoritative and legitimate leadership
6. Employ negotiating skills
7. Describe the skills required for good network governance and assurance
8. Organise effective programme management
9. Resume basic technical knowledge about networks, eHealth, knowledge generation, research, healthcare

## **TRAINING METHOD**

The course is composed of presentations held by expert speakers and interactive question & answer sessions between speakers and participants. Workshops in small groups, role-playing and wrap-up sessions will be part of the training as well.

The course will be preceded by preparatory webinars.

## **PARTICIPANTS AND REGISTRATION**

The International course is open to patient representatives involved in the 24 ERNs, including members of the European Patients Advisory Groups (ePAGs), and other RD patient advocates.

To ensure active participation and exchange with teaching staff and participants, a maximum of 30 attendees will be admitted. A selection process will be applied based on the participants' background and involvement in patient associations and ERNs. The selection of the participants will be carried out in agreement with Task Partners (EURORDIS Paris, ISS Rome, ACU/ACURARE Istanbul, MUG Gdańsk).

DRAFT



This Training has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No 825575 - European Joint Programme on Rare Diseases

## **REGISTRATION**

REGISTRATION is now open for the RESERVE LIST only at this [LINK](#) until the 29th of May 2022.

The selected participants will receive an email by the 3rd of May. The non-selected participants should consider themselves on a reserve list until the 3rd of October.

All applicants will receive an email on the status of their application (if accepted, in reserve list or not accepted) by the 3rd of October 2022.

**For important updates, deadlines and for the online registration please visit the website at the following [LINK](#)**

## **FEES AND COSTS**

The course and registration are free of charge.

The course organisers will not cover expenses incurred by the participants in any case.

## **LEARNING ASSESSMENT**

The acquired skills will be assessed during the role playing and presentation in plenary sessions. A satisfaction survey will be submitted to the participants at the end of the training course.

## **ATTENDANCE CERTIFICATES**

At the end of the course a certificate of attendance will be handed to the participants who attended 100% of the course. No credits of Continuing Education in Medicine will be issued.

## **OFFICIAL LANGUAGE**

English

## **VENUE**

ONLINE, on the Microsoft Teams Platform of the EJP RD.

The connection details will be sent by email to the selected participants some days before the start of the training course.

## **CONTACTS**

If you have questions, please write Dr. Claudio Carta: [claudio.carta@iss.it](mailto:claudio.carta@iss.it) (in Cc [laura.cellai@iss.it](mailto:laura.cellai@iss.it))

DRAFT



This Training has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No 825575 - European Joint Programme on Rare Diseases

## Programme of the Course

### DAY 1 (CET Time)

November 10, 2022

09.15 Registration

09.30 Welcome & introduction

**Domenica Taruscio, Claudio Carta, Matt Bolz-Johnson**

09.45 Ice-Breaking session

**Lenja Wiehe, Rita Francisco**

10.00 European Reference Networks (ERNs): overview & success so far and important issues for the future

**Matt Bolz-Johnson**

10.45 Integration of ERNs into national level

**Marta Mosca, Domenica Taruscio**

11.15 Coffe break

11.30 The Role of EURORDIS

**Simona Bellagambi**

11:45 The Role of National Alliances: the Italian Experience "UNIAMO"

**Annalisa Scopinaro**

12.00 The role of ePAGs within the ERNs

- Managing patient engagement in the ERNs

**Diana Marinello**

- The active and pro-active role of e-PAGs

**Michela Onali**

- How to link multi-level patient representation

**Annalisa Scopinaro**

12.45 The role of ePAGs within the community

**Claudia Crocione**

13.00 Questions and answers

DRAFT



13.30 Lunch

14.30 Round table: leading within the ERN / engaging with the community of healthcare providers

*Chairs:* **Claudia Crocione, Lenja Wiehe, Marta Mosca**

15.30 Questions and answers

16.00 End of Day

## **DAY 2 (CET Time)**

**November 11, 2022**

09.30 Public speaking: introduction to presentation skills

**Alberto Castelvechi**

09.50 Public speaking and presentation skills: simulation in small groups

**Alberto Castelvechi**

10.35 Coffee break

10.50 Public speaking: presentation in plenary of the work done in small groups and feedback from the expert

**Alberto Castelvechi**

12.20 Introduction to negotiation skills

**Marco Mastracci**

12.40 Lunch

13.30 Negotiation skills: simulation in small groups

**Marco Mastracci**

14.15 Negotiation skills: presentation in plenary of the work done in small groups and feedback from the expert

**Marco Mastracci**

15.45 Closing remarks

**Domenica Taruscio, Claudio Carta, Lenja Wiehe**

16.00 Free networking and satisfaction survey

17.00 End of the course

DRAFT



## TRAINERS

**Simona Bellagambi**, EURORDIS, Paris, France

**Matt Bolz-Johnson**, EURORDIS, Paris, France

**Claudio Carta**, National Centre for Rare Diseases, Rome, Italy

**Alberto Castelvechi**, Advisor to the President of the Senate on Institutional Relations, Rome, Italy

**Claudia Crocione**, ePAG VASCERN

**Rita Francisco**, EURORDIS, Paris, France

**Diana Marinello**, ERN ReCONNET

**Marco Mastracci**, School of Law, Washington University in St. Louis, Saint Luis, USA

**Marta Mosca**, Rheumatology Unit, Department of Internal Medicine, University of Pisa, ERN ReCONNET Coordinator, Pisa, Italy

**Michela Onali**, ePAG EURO-NMD

**Annalisa Scopinaro**, UNIAMO, Federazione Italiana Malattie Rare, Rome, Italy

**Domenica Taruscio**, National Centre for Rare Diseases, Rome, Italy

**Lenja Wiehe**, EURORDIS, Barcellona, Spain

## COURSE DIRECTOR

Claudio Carta, National Centre for Rare Diseases, ISS, Italy

## SCIENTIFIC SECRETARIAT

Marta De Sanits, Antonella Sanseverino, Domenica Taruscio, National Centre for Rare Diseases, ISS, Italy

## ORGANISING SECRETARIAT

Linda Agresta, Laura Lee Cellai, Patrizia Crialesi, Stefano Diemoz, Sandro Ghirardi  
National Centre for Rare Diseases, ISS, Italy

DRAFT

