

## GENERAL INFORMATION

The Congress is addressed to professionals in the National and International social and health network of physicians, psychologists, nurses, social workers, educators, lay groups and students involved in the field of rare disease, and more in general interested in narrative medicine. It is also particularly dedicated to affected people with rare diseases and their families.

The official languages will be Italian/English (simultaneous translation service will be available).

A total number of **80 participants** can attend the Congress.

## LOCATION

Aula Rossi, Istituto Superiore di Sanità  
Via Giano della Bella, 34 - 00161 Rome, Italy

## METHOD OF REGISTRATION

**Participation is free, but registration is required** for all meeting participants through Registration form available on

[www.surveymonkey.com/s/narrative\\_medicine\\_congress](http://www.surveymonkey.com/s/narrative_medicine_congress).

Deadline for registration: 7 June 2014.

Travel and accommodation expenses will be covered by the participants.

## CERTIFICATE OF ATTENDANCE

This will be given at the end of the Congress.

## Second International Congress NARRATIVE MEDICINE AND RARE DISEASES

13 June 2014

### SCIENTIFIC DIRECTOR

Domenica TARUSCIO

*National Centre for Rare Diseases - Italian National Institute of Health, Rome*

### SCIENTIFIC COMMITTEE

Rita CHARON

*The Program in Narrative Medicine, Department of Medicine College of Physicians  
& Surgeons of Columbia University, New York*

Guido GIARELLI

*Department of Health Sciences, University "Magna Graecia", Catanzaro*

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Domenica TARUSCIO

*National Centre for Rare Diseases - Italian National Institute of Health, Rome*

### SCIENTIFIC SECRETARIAT

Amalia Egle GENTILE, Marta DE SANTIS

*National Centre for Rare Diseases - Italian National Institute of Health, Rome*

Francesca SCAPINELLI

*Press Office - Italian National Institute of Health, Rome*

### ORGANISING SECRETARIAT

Linda AGRESTA, Patrizia CRIALESE, Norina SERPA, Sabina  
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## Second International Congress

## NARRATIVE MEDICINE and RARE DISEASES

13 June 2014

Aula Rossi  
Istituto Superiore di Sanità  
Via Giano della Bella, 34  
Rome - Italy

Second International Congress  
**NARRATIVE MEDICINE AND RARE DISEASES**

13 June 2014

10.00 *Participants registration*

10.30 **Welcome remarks**

**Session I**

*Chairpersons: Roberto LALA and Mirella TARANTO*

10.40 **From patient's stories to recommendations on narrative medicine**

Domenica TARUSCIO

11.10 **"Viverla Tutta": analysis of patient and caregiver stories collected through a national newspaper webpage**

Stefania POLVANI, Federica BIONDI, Ilaria SARMIENTO, Federico TRENTANOVE

11.40 **Consensus Conference Celebration: recommendations for the implementation of narrative medicine in clinical practice**

Sandro SPINSANTI

12.10 **From patient's stories to the healthcare system: the European S.T.o.Re. project first steps**

Amalia Egle GENTILE, Desislava DIMITROVA, Mariola MARRERO DIAZ

12.40 **General discussion**

13.15 *Lunch*

**Session II**

*Chairpersons: Paraskevi SAKKA and Domenica TARUSCIO*

14.00 **ROUND TABLE**  
**"National and International events in narrative medicine: sharing experiences and future initiatives"**

*Participants:*

Vincenzo ALASTRA  
 Annamaria DELPIANO and Patrizia RUSTIGHI  
 Amalia Egle GENTILE  
 Stefania POLVANI  
 Paolo TRENTA  
 Ivana TRUCCOLO and Nicoletta SUTER  
 Maria VACCARELLA  
 Eliana ZUIN

15.30 **General discussion**

16.15 **Conclusions**  
 Domenica TARUSCIO

16.30 *End of the day*

*Speakers and Chairpersons*

**Vincenzo ALASTRA** - Local Health Unit, Biella

**Federica BIONDI** - Health Promotion, Local Health Unit ASL 10, Florence

**Annamaria DELPIANO** - Local Health Unit 2 Liguria, Savona

**Desislava DIMITROVA** - Bulgarian Association for Promotion of Education and Science, Plovdiv

**Amalia Egle GENTILE** - National Centre for Rare Diseases - Italian National Institute of Health, Rome

**Roberto LALA** - Città della Salute e della Scienza di Torino, Turin

**Mariola MARRERO DIAZ** - University of La Laguna, Canary Island

**Stefania POLVANI** - Health Promotion, Local Health Unit ASL 10, Florence

**Patrizia RUSTIGHI** - Local Health Unit 2 Liguria, Savona

**Paraskevi SAKKA** - Greek Dementia Association, Athens

**Ilaria SARMIENTO** - Health Promotion, Local Health Unit ASL 10, Florence

**Sandro SPINSANTI** - Giano Institute, Rome - President of the Consensus Conference Jury

**Nicoletta SUTER** - IRCCS-CRO, Aviano

**Mirella TARANTO** - Press Office, Italian National Institute of Health, Rome

**Domenica TARUSCIO** - Director, National Centre for Rare Diseases - Italian National Institute of Health, Rome

**Paolo TRENTA** - Local Health Unit, Umbria 2, Foligno

**Federico TRENTANOVE** - Health Promotion, Local Health Unit ASL 10, Florence

**Ivana TRUCCOLO** - IRCCS-CRO, Aviano

**Maria VACCARELLA** - Centre for Humanities and Health, King's College, London

**Eliana ZUIN** - Training Unit, Local Health Unit, Oristano