

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.

Deadline for registration: 7 June 2014.

Travel and accommodation expenses will be born 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

Brian HURWITZ

Centre for Humanities and Health, King's College, London

Stefania POLVANI

Health Promotion, Local Health Unit ASL 10, Firenze

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
TONON, Giorgio VINCENTI

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

medicina.narrativa@iss.it - www.iss.it/cnmr



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
Elia 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

Elia ZUIN - Training Unit, Local Health Unit, Oristano