

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 language will be English (simultaneous translation service English/Italian will be available).

A total number of 220 participants can attend the Congress.

LOCATION

Aula Pocchiari, Istituto Superiore di Sanità,
Viale Regina Elena 299 - 00161 Rome, Italy

METHOD OF REGISTRATION

Participation is free, but registration is required for all meeting participants through Registration form (available on www.iss.it/cnmr).

The Registration form, fully completed, should be printed, signed and sent by fax to:

+39 (0)6 4990 4370 by 30 May 2012.

Travel and accommodation expenses will be born by the participants.

CERTIFICATE OF ATTENDANCE

This will be given at the end of the Congress.

First International Congress NARRATIVE MEDICINE AND RARE DISEASES

4 June 2012

SCIENTIFIC DIRECTOR

Domenica TARUSCIO

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

SCIENTIFIC COMMITTEE

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SCIENTIFIC SECRETARIAT

Amalia Egle Gentile, Ilaria Luzi



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First International Congress NARRATIVE MEDICINE AND RARE DISEASES

Rome

June 4th 2012

Aula Pocchiari
Istituto Superiore di Sanità
Viale Regina Elena, 299
Rome - Italy

**First International Congress
“NARRATIVE MEDICINE AND RARE DISEASES”
4 June 2012**

09.00 **Registration**

Session I

Chairmen: Domenica Taruscio and Roberto Lala (Tbc)

09.30 **Welcome to participants**

Enrico Garaci

09.45 **Introduction**

Domenica Taruscio

Watching & walking the streets of Georgian London. James Parkinson & the art of observation

10.00

Brian Hurwitz

10.45 **Discussion**

11.15 **Poster Session**

Coffee break

Session II

Chairmen: Guido Giarelli and Paola De Castro

11.45 **Writing as therapy**

Eleaine Benton

Representations and practices about complex disease in pediatric patients: narrative as a research tool

12.05

Roberto Lala

Ibsens' Ghosts: an alternative model for learning about rare diseases

12.25

Ivana Golubović

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12.45 **Discussion**

13.15 **Poster Session**

Lunch

Session III

Chairmen: Stefania Polvani and Mirella Taranto

14.15 **Literary and film representations of breast cancer**

Federica Frediani

Relevance of illness experiences on trust and help relationship between nurse and patient with thalassemia

14.35

Angela Prioletta

The Illness Experiences in an Interregional Reference Center for Rare Diseases:

14.55 **Narratives of Patients and Health Professionals**

Elisa Picco

15.15 **Discussion**

Poster Presentation

15.45 *Amalia Egle Gentile, Ilaria Luzi*

Conclusion

16.30 *Brian Hurwitz and Domenica Taruscio*

17.00 **Adjour**

Speakers and Chairmen

Elaine Benton *Kadima, Israel*

Federica Frediani *University of Italian Switzerland, Lugano, Switzerland*

Enrico Garaci *Italian National Institute of Health, Rome, Italy*

Paola De Castro *Publishing Activities, Italian National Institute of Health, Rome, Italy*

Amalia Egle Gentile *Italian National Centre for Rare Diseases, Italian National Institute of Health, Rome, Italy*

Guido Giarelli *University "Magna Graecia", Catanzaro, Italy*

Ivana Golubović *University of Belgrade, Belgrade, Serbia*

Brian Hurwitz *School of Arts & Humanities, King's College London, London*

Roberto Lala *Regina Margherita Children's Hospital - Sant'Anna, Turin, Italy*

Ilaria Luzi *Italian National Centre for Rare Diseases, Italian National Institute of Health, Rome, Italy*

Elisa Picco *ASOU San Giovanni Battista, Turin, Italy*

Stefania Polvani *Health Promotion, Local Health Unit ASL 10, Florence, Italy*

Angela Prioletta *Rome, Italy*

Mirella Taranto *Press Office, Italian National Institute of Health, Rome, Italy*

Domenica Taruscio *Italian National Centre for Rare Diseases, Italian National Institute of Health, Rome, Italy*