



RARE DISEASE DAY 2018
and
The Flight of Pegasus
The Italian artistic-literary competition dedicated to rare diseases
10th edition

Rome
26 February 2018

ISTITUTO SUPERIORE DI SANITÀ
National Centre for Rare Diseases



Joining the worldwide celebrations of the Rare Diseases Day (RDD) 2018, the event aims to raise awareness on rare conditions among the general public.

This year, the RDD theme is *Research*, cornerstone of hope and source of great expectation for millions of people and families in the world living with a rare condition. Poor understanding of the cause, diagnostic delay, no cure and no specific treatment to change the natural history of the disease are some of the demanding and challenging issues that *Research* has to solve.

This event has been conceived to connect medicine and science to life and to art in a unique fashion to disclose the cultural and social context of rare diseases, and beyond that to capture and communicate the complexity of the rare diseases through humanity, passion and emotion.

Creativity and collaboration are the soul of *Research* that has to be original, innovative and productive in pursuing novel successfully discoveries, like Art has to be rich inspiration for scientific and artistic exploration.

This experience has been achievable thanking to the contribution of many artists who participated and to an interdisciplinary group of experts (writers, poets, painters, musicians, journalists, and medical doctors) who collaborated together in analysing and selecting all art works and to whom our heartfelt thanks goes.



PROGRAM

Monday, 26 February 2018

- 09.30 Registration
- 10.00 Welcome messages
B. Lorenzin* e W. Ricciardi
- 10.10 The contribution of the Istituto Superiore di Sanità into the fields of rare diseases
D. Taruscio
- 10.25 Art, childhood and culture
A. Villani

Chairmen: Representative of UNIAMO and A.E. Gentile*

- 10.35 Literary and neurosciences in 10 lines
P. Zoccolotti
- 10.45 Visual arts and neurosciences in 10 shoots
A. Federico
- 10.55 Music and neuroscience in 10 beats
A. Polizzi

II Part

Award Ceremony

- 11:05 **Literary Arts award**
Jury: G.P. Serino, C. Cenci, M. Di Fiorino, M. Di Guardo, D. Piccini, S. Scampini, C. Sardo, F. Villani
- 11:30 **Visual Arts award**
Jury: C. Strinati, D. Barraco, C. Biasini Selvaggi, C. Crisafio, A. Federico, V. Ferrara, S. Manfredi Zavaglia
- 12:15 **Music award**
Jury: M. Luzzatto Fegiz, M. Cotto, Quartetto Guadagnini, B. Fantini, A. Sbordonì, P. Tortiglione
- 12:30 National premiere execution of the winning composition
Guadagnini String Quartet
- 12:50 Remarkable conclusions and Rare Disease Day photo shoot
Domenica Taruscio
- 13:00 End of the event



Speakers and chairmen

Antonio Federico – Department of Medical Science, Surgery and Neurosciences University of Siena, Siena

Amalia Egle Gentile – National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome

Agata Polizzi – National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome

Representative* – UNIAMO FIMR Onlus, Italian Rare Diseases Federation, Rome

Domenica Taruscio – National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome

Alberto Villani – President of the Italian Society of Paediatrics, Rome

Pierluigi Zoccolotti – Department of Psychology, "Sapienza" University of Rome, Rome

Members of Jury

Gian Paolo SERINO, Literary critic and writer (President of Jury)

Daniele BARRACO, Photographer

Cesare BIASINI SELVAGGI, Editorial Director "Exibart"

Cristina CENCI Anthropologist, expert in social media and narrative medicine

Massimo COTTO, Journalist, dj and writer

Claudia CRISAFIO, Curator of the Festival "Uno Sguardo Raro"

Mario DI FIORINO, Psychiatrist and cultural promoter

Marina DI GUARDO, Writer

Bernardino FANTINI, Medical Historian, expert in music and emotion

Antonio FEDERICO, Professor of Neurology, expert in Art and Neurosciences

Vincenza FERRARA, Art Historian, expert in ICT and learning

Mario LUZZATTO FEGIZ, Journalist, Music critic and writer

Sveva MANFREDI ZAVAGLIA, Art curator

Daniele PICCINI, Poet and literary critic

QUARTETTO GUADAGNINI, Fabrizio Zoffoli violin, Cristina Papini violin, Matteo Rocchi viola, Alessandra Cefaliello cello

Carmelo SARDO, Journalist and writer

Alessandro SBORDONI, Composer

Sabrina SCAMPINI, Journalist and writer

Claudio STRINATI, Historian and Art critic

Paolo TORTIGLIONE, Composer

Flavio VILLANI, Neurologist and writer

Scientific director

Domenica Taruscio

National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome

Scientific coordinators

Patrizia Crialesi, Amalia Egle Gentile, Agata Polizzi, Angela Ruocco, Antonella Sanseverino

National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome

E-mail concorsopegaso@iss.it; phone +39 06 4990 4373/4410

Organizing secretariat

Linda Agresta, Daniela Bernardo, Giuseppe Bernardo, Luana Bernardo, Federico De Paulis,

Stefano Diemoz, Daniele Savino, Andrea Vittozzi

National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome

E-mail contact.cnmr@iss.it; phone +39 06 4990 4418

Press office

Gerolmina Ciancio, Mirella Taranto

Istituto Superiore di Sanità, Rome



GENERAL INFORMATION

Venue: Aula Pocchiari, Istituto Superiore di Sanità

Entrance: Viale Regina Elena, 299, Roma

Targets and number of participants

The event is addressed to people with rare diseases, families, health professionals and anyone interested. A maximum of 200 people will be admitted to participate.

How to register

Participation is free, but it is necessary to register online at

https://it.surveymonkey.com/r/RDD_Xedizione by 22 February 2018

Travel and accommodation costs are to be paid by the participant

Participants will be selected according to the order of registration of the online application form

Certificate

A certificate of attendance will be sent via e-mail to those who request it

Preliminary Programme