

Everybody knows the important progress the genetics has made in the last few years, giving rise to much controversy and debates. On the one hand there are great new hopes for the treatment of human diseases; on the other there are fears and doubts for the consequences which could be caused by the genetic manipulations. Among the many effects resulting from the scientific and cultural progress it should have to be pointed out with more emphasis the better knowledge and participation of the families coping day by day with a genetic problem. Better knowledge and awareness induced many parents of children suffering of rare genetic diseases to take active part in organizing support groups with a mission of mutual help and collection of funds for the study of specific genetic diseases.

The Ring14 Association is one of the more recent supporting groups created with the aim of promoting knowledge and research on a rare syndrome caused by a rearrangement of chromosome 14 in the shape of a ring, recently extended also to all syndromes related to chromosome 14 alterations.

In a short time the Ring14 Association has achieved very important and unexpected results: it created contacts among families concerned with these pathologies all over the world; it involved doctors and researchers, collected funds for research, brought people to know the existence of a so rare genetic disease. Last but not least, the Association is now organizing an international scientific congress representing a further important step towards the final goal of all support groups that is the cure of rare genetic diseases.

We well aware that the road towards this goal will be long and difficult, but we also know that we can reach it only through a serious, consistent and patient effort in clinical and laboratory research. The Ring 14 Congress is a concrete testimony of our commitment.

RAPPORTEURS

<i>D. W. Cox (Alberta, Canada)</i>	<i>A. Dalla Vecchia (Reggio E.)</i>
<i>R. Ciccone (Padova)</i>	<i>G. Giachetti (Reggio E.)</i>
<i>L. Seminara (Roma)</i>	<i>P. Martinelli (Reggio E.)</i>
<i>M. Zollino (Roma)</i>	<i>P. Fagandini (Reggio E.)</i>
<i>A. Scarano (Reggio E.)</i>	<i>G. Fronticelli (Modena)</i>
<i>S. Giovannini (Bologna)</i>	<i>L. Di Giorgio (Verona)</i>
<i>E. Della Giustina, (Reggio E.)</i>	<i>I. Soncini (Reggio E.)</i>
<i>C. Fusco (Reggio E.)</i>	<i>V. Ferretti (Reggio E.)</i>
<i>G. Gobbi (Bologna)</i>	<i>C. Imprudente (Bologna)</i>
<i>S. Grosso (Siena)</i>	<i>S. Negri (Bologna)</i>
<i>C. Pettinato (Bologna)</i>	<i>R. Alves (Brasil)</i>
<i>M. Filippini (Bologna)</i>	<i>D. Bruni (Italy)</i>
<i>M. Brini (Reggio E.)</i>	<i>A. Bormida (Italy)</i>
<i>S. Amarri (Reggio E.)</i>	<i>S. Tandy (Great Britain)</i>
<i>C. Ruggerini (Modena)</i>	<i>L. Jhones (Great Britain)</i>
<i>A. Castellani (Verona)</i>	<i>F. Gaillard (France)</i>

GENERAL INFORMATION

SIMULTANEOUS TRANSLATION:
The conference will be simultaneously translated into English language.

CONGRESS SEAT: Hotel Mercure Astoria 4*
Viale Leopoldo Nobili, 2 42100 Reggio Emilia
Tel. (39)0522 435245 Fax (39)0522 453365
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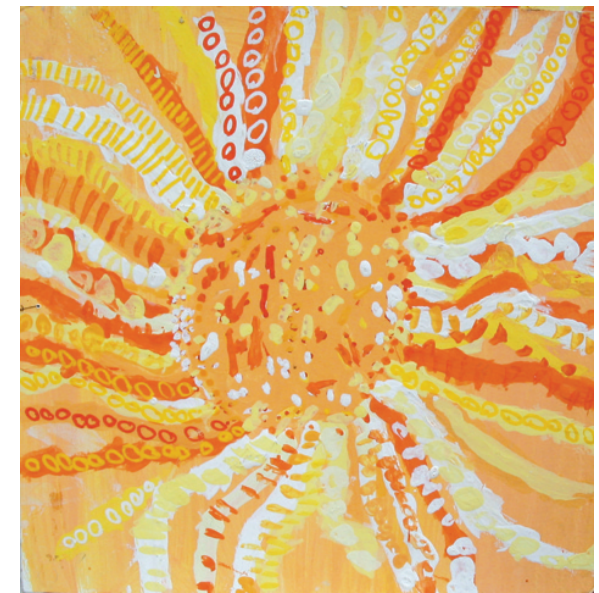
HOTEL ACCOMODATION:
For hotel reservation you can avail yourselves of the booking form available on our web site www.ring14.com or getting in touch with our organizing secretariat.

ACTS:
The acts will be published on CD which will be included in the Congress Kit.

ENTRANCE FORMALITIES:
In order to allow us to welcome you at the best, please send the entrance form by fax or by mail to our organizing secretariat within 02.10.2006.

Organizing secretariat
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1st INTERNATIONAL CONGRESS ASSOCIATION



For research on rare neurogenetic diseases
Non profit support group

*FROM THE CLINICAL
AND GENETIC MANAGEMENT
TO THE DOMESTIC MANAGEMENT
OF THE AFFECTED CHILDREN*

Reggio Emilia
13 - 14 october 2006

GENERAL PROGRAM

12th OCTOBER - thursday

In the afternoon it will take place a round table with the parents for presenting the activities, exchanging experiences and opinions. It will be also evaluated the proposals for opening Ring14 supporting seats abroad.

13th OCTOBER - friday

09,00-09,30 a.m. welcome authorities and President RING 14

GENETIC PROBLEM AND PHENOTYPICAL CORRELATIONS

Moderators: *Giovanni Neri (Roma) - Giuseppe Gobbi (Bologna)*

09,30-10,00 a.m. Research on Genes-Epilepsy in the RING14 syndrome - *Diane W. Cox, Alberta, Canada*

10,00-10,30 a.m. "When diagnosis is elusive: new frontiers of cytogenetic" - *Roberto Ciccone (Padova)*

10,30 a.m. Discussion

10,45 a.m. Coffee break

Moderators *Gianfranco Croci (Reggio E.) Maria Brini (Reggio E.)*

11,00-11,30 a.m. Basing genetic defect in Ring14 syndrome and in the syndromes with partial deletion 14q - *Laura Seminara (Roma)*

11,30-12,00 p.m. Genotype-phenotype correlations in syndromes from rearrangements of chromosome 14: delineation of a phenotypical map for the research of gene-disease - *Marcella Zollino (Roma)*

12,00 p.m. Discussion

12,30-2,00 p.m. FREE lunch with optional proposal of buffet at the Hotel's Restaurant

ROUND TABLE: THE CLINICAL MEDICINE

Moderators: *Paolo Balestri (Siena) - Elvio Della Giustina (Reggio E.)*

2,00-2,30 p.m. "Utility of data base and protocols for rare genetic diseases in clinical genetics research: RING14 experience"

Angela Scarano (Reggio E.) Simona Giovannini (Bologna)

2,30-3,00 p.m. "General clinical aspects and neurologic research" - *Elvio Della Giustina (Reggio E.) - Carlo Fusco (Reggio E.)*

3,00-3,30 p.m. "Epilepsy" - *Giuseppe Gobbi (Bologna)*

3,30-4,00 p.m. "Antiepileptic treatment in Ring14"

Salvatore Grosso (Siena)

4,00 p.m. Coffee break

Moderators: *Norina Marcello (Reggio E.) - Sergio Amarri (Reggio E.)*

4,30-5,00 p.m. "Rule of PET and SPM software in the research of epileptic centres" - *Cinzia Pettinato (Bologna)*

5,00-5,30 p.m. "The neuropsychologic profile"

Melissa Filippini (Bologna)

5,30-5,45 p.m. "The immunity aspects" - *Maria Brini (Reggio E.)*

5,45-6,00 p.m. "Gastrointestinal diseases and nutrition support"

Sergio Amarri (Reggio E.)

ROUND TABLE: Discussion

6,00 p.m. End of the first day of Congress

8,00 p.m. Gala dinner (optional) in Hotel

Contemporaneously with the Congress there will be operative, always inside the Hotel Astoria, a playing room where the children will be entertained by voluntary assistants.

14th OTTOBER - saturday

ROUND TABLE: FROM DISABILITY TO ABILITY

Moderators: *Franco Nardocci (Rimini)*

and *Elisabetta Fréjaville (Bologna)*

09,00-09,30 a.m. "The actual conception of mental delay (according to AAMR and ICF): possible implications in genetic syndromes"

Ciro Ruggerini (Modena)

09,30-10,00 a.m. "Re/habilitating Strategies and Techniques in the intellectual disability"

Alessandro Castellani (Verona)

10,00-10,30 a.m. "Taking charge of the child and his family in a treatment system"

Annamaria Dalla Vecchia (Reggio E.)

10,30 a.m. Coffee-break

10,45-11,15 a.m. "To do for learning, to learn for doing"

Giuliana Giachetti (Reggio E.)

11,15-11,45 a.m. "Brothers and sisters: special members in extraordinary families"

Paola Martinelli (Reggio E.)

11,45-12,15 a.m. "When a diagnosis change your life"

Pergiuaseppina Fagandini (Reggio E.)

12,15 p.m. Discussion

12,30-2,00 p.m. FREE lunch with optional proposal of buffet at the Hotel's restaurant

ROUND TABLE:

THE ITALIAN EXPERIENCE BETWEEN SCHOOL INTEGRATION AND TREATING SYSTEM

Moderators: *Luciano Rondonini (Reggio E.)*

Sandra Piccinini (Reggio E.)

2,00-2,30 p.m. "Improving Communication and children with Mental Delay"

Giovanni Fronticelli (Modena)

2,30-3,00 p.m. "Psychopedagogic valencies of the play when approaching the disabled subject in evolving age" - *Luisa di Giorgio (Verona)*

3,00-3,30 p.m. "The infant school as an important opportunity of knowledge, education, research and rehabilitation" - *Ivana Sencini (Reggio E.)*

3,30-4,00 p.m. "A rich school of everybody"

Valeria Ferretti (Reggio E.)

4,00 p.m. Coffee break

4,15-4,45 p.m. "The casket and the pirates. The adventure of integration among wrecks, brave captains and discovery of hidden treasures" - *Claudio Imprudente (Bologna); Sandra Negri (Bologna)*

4,45-5,35 p.m. Direct experiences:

4,45 p.m. "Under-diagnostics: a problem of accessibility or connectivity" *D.ssa Rita Alves - Brazil*

4,55 p.m. "We were alone Now we are a lot"

Daniela Bruni - Italy

5,05 p.m. "When diagnosis arrives after 32 years of wait"

Anna Bormida - Italy

5,15 p.m. "From Mozambique to Great Britain taking care of "special children" between nature and civilization"

Sheena Tandy - Great Britain - Mozambique

5,25 p.m. "Finding, understanding and hope"

Lisa Jhones - Great Britain

5,35 p.m. "Structured rehabilitations to be carried out at home following the methods Montessori, TEACCH and ABA ... , how to organise the family in order to apply the various learning methods"

Florence Gaillard - France

5,45-6,00 p.m. "And after what we are going to do? The future of RING14" - *Stefania Azzali (Reggio E.)*

6,00 p.m. Discussion

6,15 p.m. Delivery questionnaire and ECM form

6,30 p.m. End of the Congress

8,00 p.m. Dinner (optional) in Hotel

Contemporaneously with the Congress there will be operative, always inside the Hotel Astoria, a playing room where the children will be entertained by voluntary assistants. Furthermore, medical examinations of the children will be carried on by our four consulting physicians.