**3rd Ring14 CONGRESS FOR FAMILIES AND MEDICAL RESEARCHERS**

**5-6 SEPTEMBER 2015**

**HOTEL MATILDE DI CANOSSA Canossa (RE)** <http://www.hotel-matildedicanossa.it/>

**Saturday, September 5**
**9: 00-13: 00 Update on scientific and clinic activities**

 9: 00-09: 20 Greetings and introduction (Azzali)

 **Session 1 - clinical (chairperson: G. Neri)**

9: 20-9: 40 "Main aspects of clinical genetic Ring (14)" syndrome (G.Neri)

 9: 40-10: 00 “Epilepsy and neurologic aspects in chromosome 14 syndromes” (G.Gobbi)

10: 00-10: 20 "Immunity and respiratory infections in chromosome 14 syndromes " (A. Soresina)

10: 20-10: 40 "Care of clinically complex children and gastroenterological and nutritional support " (S. Amarri)

 **10:40-11:10 Coffe break**

 **Session 2 - scientific activity (chairperson: M. Crimi)**

11:10-11:30 "Why a scientific office in a parent association?" (M.Crimi)

# 11:30-11:50 “RING14 syndrome: towards a detailed genotype-phenotype correlation” (O. Zuffardi)

11:50-12:10 "From medical research projects: the role of the clinical data-base" (B. Rinaldi)

12:10-12:30 "The Telethon Network of Genetic Biobanks and patient associations: the experience of the agreement with the Association Ring 14 “ (C. Baldo)

12: 30-13: 00 Final discussion and queries from families about pressing issues

 **13:00-14:00 Lunch**

 **14:00-16:30 Roundtable with clinicians / researchers on:**

14:00-14:30 Clinical center network (G. Neri)

14:30-15:00 PDTA (B. Rinaldi)

15:00-15:30 SSN Guidelines (G. Gobbi)

15:30-16:00 Horizon 2020 and other opportunities (M. Crimi)

16:00-16:30 Final discussion

 **14: 00-17: 00 Meeting between the delegates of Ring14 International**
19:00 Dinner at San Marco parish.
21:00 Gospel concert of REGOSPELCORO at San Marco parish.

**Sunday, September 6**

**Session 3 - Linguistic and cognitive development (chair: S. Azzali)**

09: 00-09: 10 Greetings and introduction (S. Azzali)

09:10-09:30 " Communication and language development in children with abnormal chromosome 14"
(L. Zampini)

09:30-09:50 "The autistic disorders spectrum in chromosome 14 syndromes" (P. Visconti)

09:50-10:10 "The behaviors problems: management, prevention, education" (F. Cavallin)

10:10-10:30 Discussion

 **10:10-10:50 Coffee break**

**Session 4 – Social integration and Family (chair: S. Azzali)**

10:50-11:10 "Routes with disabilities in families: which resources and difficulties in the system fraternal? How to protect it? " (M. Frare / R. Gori + personal comments from sibilings)

11:10-11:30 "The fear: a resource for inclusion. History of an experience " (A. De Mitri – I. Antonioli)

11:30:11:50 “A future togheter: Ring14 International” (S.Azzali + chapters representtives)

11:50-12:30 Discussion

 **12:30 Lunch

14: 00-16: 00 Meeting between the delegates of Ring14 International**

**OTHER INFORMATION:**
In both mornings the children will be managed by our volunteers in the ratio 1: 1 supervised by professionals of ABA therapy in the playroom.

The both mornings meetings will be translated simultaneously in English

The two afternoons will be dedicated to families offering them leisure activities at the hotel organized by volunteers of the Cooperative Solidarity 90 such as: music and songs, clowns, theater, soap bubbles, balloons, painting, tattoos, face painting, narrastorie, outdoor games and races.

It will be simultaneously carried out medical examinations and blood tests and skin to be sent to the bio bank with the help of Red Cross volunteers who will assist families and then will deliver them to the Biobank Galliera.

The brothers over 16 years old will be joined on both days to social media managers helping them in various social activities.

The association Ring14 Italy will offer food and lodging to the Italian families claiming expenses.