

Organizing Committee

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Ministero della Salute

ROMA 



The 8th CCI Europe Regional Conference

Con il sostegno di:  **FONDAZIONE
CON IL SUD** per il progetto "Insieme per Crescere"

Rome, Hotel Quirinale
May 12-13-14, 2017

CCI

Formed in 1994, **Childhood Cancer International** is now the largest patient support organization for childhood cancer (www.childhoodcancerinternational.org). It is a global network of parents groups, survivor associations, national organizations and childhood cancer support organizations, working with and supporting children and adolescents with cancer, survivors and their families. CCI has 181 member organizations in 90 countries, across 5 continents. Of these, 20 are national networks.

CCI believes that sharing knowledge stimulates growth of innovations and new ideas for creating more responsive programs and more effective ways to serve, support and assist. We share information and experiences, promote best practices and good practice models, adapt effective, innovative approaches and deliver cost effective solutions to responsibly address challenges faced by children and adolescents with cancer, survivors and their families.

FIAGOP

FIAGOP is the umbrella organization representing about 30 Italian Parent Associations committed to support children and adolescents with cancer and their families. It was founded in 1995 with the aim to strengthen their role at a national level, foster communication and provide mutual support, promote awareness on Pediatric Oncology.

FRIDAY, MAY 12th

12:30 Registration

14:00 CCI Introduction

Carmen Auste | Chair CCI
Ruth Hoffman | Vice - Chair CCI

Opening CCI Europe Regional Conference

CCI Europe Regional Committee (CCI-E ReC)
MODERATORS: *Luisa Basset, Anita Kienesberger*

15:30 Presentation of the survey about commitment of parents' associations in Italy to support pediatric oncology and hematology

Angelo Ricci | President FIAGOP (Italian Federation of Oncology Parents' Association)
MODERATORS: *Nicole Scobie, Holly Wattwill*

15:45 PACT - International Program of Action for Cancer Therapy: Main activities and partnership opportunities

Anja Nitzsche-Bell | IAEA (International Atomic Energy Agency)
MODERATORS: *Nicole Scobie, Holly Wattwill*

16:00 Coffee break

16:30 Parallel Sessions

Workshop Establishing a fundraising strategy for a Childhood Cancer NGO

Anna Bürgi, Felicitas Dunekamp | Childhood Cancer Switzerland

Workshop Survivors in Europe: Moving forward into a successful future

All survivors
MODERATORS: *CCISN (CCI Survivors Network) / Peter Lack*

18:00 Market Place

19:30 Dinner

SATURDAY, MAY 13th

MODERATOR: *Angelo Ricci*

09:00 The role of the Italian Association of Paediatric Haematology and Oncology (AIEOP)

Franca Fagioli | AIEOP President, Italy

09:15 The AIEOP central diagnosis review project in pediatric oncology and hematology

Paola Quarello | AIEOP, Italy

MODERATORS: *Luisa Basset, Anita Kienesberger*

09:30 Cancer in children and adolescents in Europe: Current situation and perspectives

Martin Schrappe | SIOPE President

09:45 JARC (Joint Action on Rare cancer) - What does it mean for the patients' and survivors' community?

Olga Kozhaeva | SIOPE office

10:00 Lessons learned from ExPO-r-Net and the way forward in the ERN PaedCan ExPO-r-Net (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment) / ERN PaedCan (European Reference Network for Paediatric Cancers)

Melanie Brunhofer | (CCRI - Children's Cancer Research Institute Vienna)

10:30 Coffee break

11:00 ePAGs (European Patient Advocacy Groups) within European Reference Networks

Matt Johnson, Ariane Weinman | EURORDIS

11:15 Questions & Answers

11:30 The Survivorship Passport: What is needed for its implementation in every country

Riccardo Haupt | Istituto Giannina Gaslini, Italy

MODERATOR: *Carina Schneider*

**12:00 Parallel Session
Workshop** Survivorship Passport (SUPA)

The European Survivors' view on implementation, research and empowerment

All survivors

MODERATOR: *Angelo Ricci*

12:00 Presentation of a football event played by survivors team from all over Italy

Andrea Ferrari | Istituto Nazionale Tumori, Italy

12:10 Presentation of photo project and marathon fundraising activity

Signý Gunnarsdóttir, Sveinn Benedikt Rögnvaldsson | Styrktarfélag Krabbmeinsjúkra barna, Iceland

12:20 Cancer will not be our faith

Sezin Soylu | (LÖSEV Uluslararası İlişkiler, Turkey)

12:30 Unite2Cure

- update from the European movement for better treatments
- age of entry into trials

Christopher Copland, Anne Goeres, Nicole Scobie | United2Cure

13:00 Lunch

MODERATORS: *Peter Lack, Birgitta Setz*

15:00 The Importance of memory

Anne Goeres | Foundatioun Kriibskrank Kanner, Luxembourg

15:10 European Retinoblastoma Awareness Campaign - "Weiß sehen"

Jennifer Ziegler | ÖKKH - Austrian Childhood Cancer Organization
Sabine Kuenzel | KAKS - Childrens' Eye Cancer Foundatioun Germany

15:20 "Sternentaler"

Brigitte Trümppy | Switzerland

15:40 Coffee break

MODERATORS: *Jaap den Hartogh, Jennifer Ziegler*

16:10 E-connected classroom for cancer-sick children

Anne Goeres | Foundatioun Kriibskrank Kanner, Luxembourg

16:20 Change for life TV

Ludmila Hurajova | Smile n.o., Slovakia

16:30 Firefly Youth

Dragan Cvitić, Ana Radunic | Firefly, Croatia

16:40 GROUP PICTURE

17:30 Sightseeing Tour

19:30 Dinner off-site

SUNDAY, MAY 14th

09:00 Survivors in Europe - Striving forward together

All survivors

09:40 Coffee break

MODERATORS: *Luisa Basset, Anita Kienesberger*

10:00 Interactive session (Main topic: ExPO-r-Net / ERN PaedCan)

CCI-E ReC

11:00 CCI Closing Session

CCI-E ReC

13:00 Lunch