

ICCCPO	Survivors
<p>Thursday, October 2nd</p> <p>Time: 12.30 – 14:00 Activity: Lunch Location: Room 3 Sponsor: Een Häerz fir kriibskrank Kanner, Luxembourg</p> <p>Time: 14.00 – 15:30 Activity: Workshop: Best fundraising projects. Chair: Christine Wandzura, Canada Location: Room 3 Sponsor: Swedish Childhood Cancer Foundation, Barncancerfonden</p>	<p>Wednesday, October 1st Time: 15.00 – open Activity: Social activities and get together Chairs: Dorothee Schmid, Germany Location: Outside Estrel</p> <p>Thursday, October 2nd Time: 09.00 – 12.30 Activity: Welcome & Introductions Chairs: Alexandra Brownsdon, UK Location: Estrel room 4 09.00: Welcome & Introductions - Alexandra Brownsdon, UK 10.00: Get to know you activities - Maren Bösel 11.00: Invited Group Presentations (10 minutes each) Neelima Dalvi, India, Abstract #345 What did the 39th SIOP do for Indian Childhood Cancer Survivors. Kyttaro – Greece – Emily Tsirou CanTeen – Ireland – Gordon Brady & Liam Quinn (TBC) Cancer Busters – Indonesia – Saprita Tahir 11.45: Workshop: Mentoring Marieke Van de Wetering, The Netherlands Sponsor: CLIC Sargent ,UK</p> <p>Time: 12.30 – 14:00 Activity: Lunch Location: Room 3 Sponsor: Een Häerz fir kriibskrank Kanner, Luxembourg</p> <p>Time: 14.00 – 15:30 Activity: Survivors Workshops Chair: Alexandra Brownsdon, UK Location: Room 4 14.00 Leadership Speaker: Dorothee Schmid, Germany 14.45 Stress Speaker: Alexandra Brownsdon, UK Sponsor: CLIC Sargent ,UK</p>

Time: 16:00 – 17:30
Activity: Workshop: Caring for the care givers.
Chair: John Spinetta, U.S.
Location: Room 3
Sponsor: Swedish Childhood Cancer Foundation, Barncancerfonden

Time: 16.00 – 17:30
Activity: Workshop: How to set up and maintain parent houses
Chairs: Sadie Cutland, South Africa and Gerlind Bode, Germany
Location: Room 30341
Sponsor: Swedish Childhood Cancer Foundation, Barncancerfonden

Time: 19.00 – 22.00
Activity: Meet and Greet – all groups are asked to bring some food or beverage from their country. *
Hosts: Benson Pau, China & Gerlind Bode, Germany
Location: Room 2
Sponsor: German Kinderkrebsstiftung

*
As the Meet & Greet takes place in the Estrel, the hotel is responsible for it and for hygienic reasons will not allow any fresh food such as raw fish or meat. Everything will have to be packed, canned or sealed in plastic foil.

Friday, October 3rd

Time: 9.00 – 9.30
Activity: ICCCPPO Opening Ceremonies
Chairs: Anders Wollmén, Sweden and Anita Kienesberger, Austria
Location: Room 3
Speakers: Günter Henze, Germany, Chairman Local Organizing committee
Benson Pau, China, Vice-chairman, ICCCPPO
Alexandra Brownsdon, UK, ICCSN
Gerlind Bode, Germany, LOC

Time: 9.30 – 10.30
Activity: Keynote Address: New Horizons; What does that mean?
Chairs: Anders Wollmén, Sweden and Anita Kienesberger, Austria
Location: Room 3
Speakers: Robert J. Arceci. U.S.

Time: 16.00 – 17:30
Activity: Survivors Workshops – Survivor Groups – Set up, Experiences, Challenges
Chair: Alexandra Brownsdon, UK
Location: Room 4
Sponsor: CLIC Sargent ,UK

Time: 19.00 – 22.00
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Location: Room 3
Speakers: Robert J. Arceci. U.S.

<p>Time: 11.00 – 12.30 Activity: Opening Plenary Session Chairs: Simon Lala, New Zealand & Kenneth Dollman, South Africa Location: Room 3 Speakers: Dorothee Schmid, Germany “Care for long term survivors – from the survivors’ point of view” Carole Easton, UK Abstract #979 “Surviving Childhood Cancer: A UK Perspective” Christina Stefan, South Africa “Adolescents with childhood cancer: How can we meet their specific needs”</p>	<p>Time: 11.00 – 12.30 Activity: Opening Plenary Session Chairs: Simon Lala, New Zealand & Kenneth Dollman, South Africa Location: Room 3 Speakers: Dorothee Schmid, Germany “Care for long term survivors – from the survivors’ point of view” Carole Easton, UK Abstract #979 “Surviving Childhood Cancer: A UK Perspective” Christina Stefan, South Africa “Adolescents with childhood cancer: How can we meet their specific needs”</p>
<p>Time: 12.30 – 14.00 Activity: Info Market and lunch Location: Estrel Foyer 1 Sponsor: Een Häerz fir kriibskrank Kanner, Luxembourg</p>	<p>Time: 12.30 – 14.00 Activity: Info Market and lunch Location: Estrel Foyer 1 Sponsor: Een Häerz fir kriibskrank Kanner, Luxembourg</p>
<p>Time: 14.00 – 15.30 Activity: “Impact on the family”. (20 minutes each) Chairs: Edith Grynszpanholc, Argentina & Poonam Bagai, India Location: Room 3 Speakers: Mei Sitaresmi, Indonesia, Abstract # 624 “Health-related quality of life assessment in Indonesian childhood acute lymphoblastic leukemia” S. Seth, V. Bhatia, V. Thavaraj, L.S. Arya, Rachna Seth, S. Saharan, L. Narayanan, India, Abstract # 559 “ Living beyond cure - Paediatric cancer survivors: Indian Scenario” Akiko Ogata, Japan, Abstract # 488 “The relationship between the perception of child health and psychological problems of the mother of childhood cancer survivors” Emma Hovén, Sweden, Abstract # 473 “ Adult survivors of childhood CNS tumours: Persistent health care needs and long-term impact on family”</p>	<p>Time: 14.00 – 15.30 Activity: Workshop: Survivor’s situation Chairs: Alexandra Brownsdon, UK, ICCSN Location: Room Paris Time: 14:00-15:00 Speakers: Dorothee Schmid, Germany Carole Easton, UK Christina Stefan, South Africa</p>
<p>Time: 15.45 – 16.45 Activity: Invited speakers and free papers, Parents Chairs: Ira Soelistyo, Indonesia & Luisa Basset, Spain Location: Room 3 Speakers: Anja Borgmann, Germany (30 min), Having Children after Surviving Cancer in Childhood or Adolescence Sven Gottschling, Germany, Abstract # 141 (30 min)“ Complementary and alternative medicine in paediatric oncology”</p>	<p>Time: 15.00 – 15.30 Activity: ICCSN Update Location: Room Paris Speakers: Alexandra Brownsdon, UK, ICCSN</p> <p>Time: 15.45 – 16.45 Activity: Invited speakers and free papers, Parents Chairs: Ira Soelistyo, Indonesia & Luisa Basset, Spain Location: Room 3 Speakers: Anja Borgmann, Germany (30 min), Having Children after Surviving Cancer in Childhood or Adolescence Sven Gottschling, Germany, Abstract # 141 (30 min)“ Complementary and alternative medicine in paediatric oncology”</p>

<p>Time: 18.30 – 20.00 Activity: SIOP Opening Ceremonies Location: Hall A&B</p> <p>Time: 20.00 – open end Activity: SIOP Welcome Reception Locations: Hall A, B, C, Foyer 1 and Foyer 3</p> <p>Saturday, October 4th Time: 09.00 – 10.00 Activity: SIOP Opening Lecture Location: Hall A+B</p> <p>Time: 10.30 – 12.00 Activity: Childhood Cancer Registries: local, national and international implications Chair: Julian Cutland, South Africa & Natasha Kotlar-Trajkovako, Macedonia Location: Room 3 Speakers: Ira Soelistyo, Indonesia, Abstract #527 (20 min) “The role of parent organization in data assessment in childhood cancer in Indonesia” Olle Bjork, Sweden, (30 min) “Childhood Cancer Incidence and Survival in Sweden 1984 – 2005”. Peter Kaatsch, Germany, (40 min) “German Childhood Cancer Registry -- possibilities and limits within the international context”</p> <p>Time: 12.00 – 14.00 Activity: Info Market Location: Estrel Foyer 1</p> <p>Time: 14.00 – 15.30 Activity: ICCCPPO Interactive Board Session - Closed session. Parent Organizations and Survivors network Only Chair: Benson Pau, China Location: Room 3</p> <p>Time: 16.00 – 16.30 Activity: Schweisguth Prize Lecture Chair: Tim Eden UK Location: Hall A & B</p>	<p>Time: 18.30 – 20.00 Activity: SIOP Opening Ceremonies Location: Hall A&B</p> <p>Time: 20.00 – open end Activity: SIOP Welcome Reception Locations: Hall A, B, C, Foyer 1 and Foyer 3</p> <p>Saturday, October 4th Time: 09.00 – 10.00 Activity: SIOP Opening Lecture Location: Hall A+B</p> <p>Time: 10.30 – 12.00 Activity: Survivor Program Chairs: Dorothee Schmid, Germany Location: Paris Speakers: Cancer & Physical Activities – Chris Maier, Germany Bicycling German survivors - Christiane Stommel, Astrid Zehbe, Nicole Klautd, Germany</p> <p>Time: 12.00 – 14.00 Activity: Info Market Location: Estrel Foyer 1</p> <p>Time: 14.00 – 17.30 Activity: Survivors activity. Survivors only Chair: Dorothee Schmid Location: Berlin Sight Seeing tour</p>
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Time: 16.45 – 18.00
 Activity: ICCCPPO Annual General Assembly - Closed session. Parent Organizations and Survivors network Only
 Chair: Benson Pau, China
 Location: Room 3

Time: 19.00 – 23.00
 Activity: ICCCPPO Annual Dinner
 Hosts: ICCCPPO Board and Gerlind Bode, German Kinderkrebsstiftung
 Location: Restaurant Alte Pumpe (directions will be handed out)
 Sponsor: German Kinderkrebsstiftung

Sunday, October 5th

Time: 08.30 – 10.00
 Activity: Meet the experts, ICCCPPO
 Chairs: Christine Wandzura, Canada
 Location: Room 3
 Experts: Leukemias/Lymphomas:
 Martin Schrappe, Germany
 Willem Kamps, The Netherlands

Solid Tumours:
 Norbert Graf, Germany
 Frank Berthold, Germany
 Heribert Jürgens, Germany
 Thomas Klingebiel, Germany
 Richard Spicer, The Netherlands

Time: 10.30 – 12.00
 Activity: “Member projects”. (15 minutes each)
 Chair: Irina Ban, Serbia & Alejandre-Castillo Guadalupe, Mexico
 Location: Room 3
 Speakers: Cécile Galzy, France, Abstract # 561 “ French parents union working together with government”
 Jocelyn Lamont, Canada, Abstract # 166 “Smiling siblings watercolour workshops”
 Shambhu Kadariya, Nepal, Abstract # 113 “Total management of cancer awareness to rehabilitation for childhood cancer”
 Jocelyn Lamont, Canada, Abstract # 76 “Dell Cyberkids”
 Marianne C. Naafs-Wilstra, The Netherlands “The ‘KanjerKetting’: A structured reward system for children with cancer.”

Time: 19.00 – 23.00
 Activity: ICCCPPO Annual Dinner
 Hosts: ICCCPPO Board and Gerlind Bode, German Kinderkrebsstiftung
 Location: Restaurant Alte Pumpe (directions will be handed out)
 Sponsor: German Kinderkrebsstiftung

Sunday, October 5th

Time: 08.30 – 10.00
 Activity: Meet the experts, Survivors
 Chairs: Rafael Feybli, Switzerland. Alexandra Brownsdon, UK (TBC)
 Location: Paris
 Experts: Leukemias/Lymphomas:
 Martin Schrappe, Germany
 Willem Kamps, The Netherlands

Solid Tumours:
 Norbert Graf, Germany
 Frank Berthold, Germany
 Heribert Jürgens, Germany
 Thomas Klingebiel, Germany
 Richard Spicer, The Netherlands

Time: 10.30 – 12.00. Survivors only
 Activity: Survivors program
 Chair: Alexandra Brownsdon, UK
 Location: Room Paris
 Speakers: Remembrance – Christine Randell, Germany (TBC)
 Feedback and Debrief - Alexandra Brownsdon, UK

Time: 14.00 – 15.30
Activity: Shared Care: Joint session with SIOP Nurses
Chair: Rachel Hollis, U.K. & Marianne C. Naafs-Wilstra, The Netherlands
Location: Hall A
Speakers: TBA

Time: 16.00 – 17.30
Activity: Hospital visit
Location: Charité Virchow-Klinikum

Time: 19.00 – 23.00
Activity: SIOP Annual Dinner
Location: German Historical Museum.
ICCCPO Parents and Survivors are welcome to participate but please observe that pre purchase of tickets is required.

Time: 14.00 – 15.30
Activity: Shared Care: Joint session with SIOP Nurses
Chair: Rachel Hollis, U.K. & Marianne C. Naafs-Wilstra, The Netherlands
Location: Hall A
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Time: 19.00 – 23.00
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Location: German Historical Museum
ICCCPO Parents and Survivors are welcome to participate but please observe that pre purchase of tickets is required.

Monday, October 6th

No specific ICCCP program. Parents and Survivors are always welcome to visit other sessions. The following sessions could be of interest for parents and survivors;

- Time: 08.30 – 10.00
 Activity: Nurses VI: Supportive care and symptom management.
 Chair: G. Cristiano, Switzerland, C. Beisel, Germany
 Location: Hall A
- Time: 14.00 – 15.30
 Activity: International Working Group Teenage and Young Adults
 Chair: T. Eden, U.K. & R. Barr, Canada
 Location: Room 1
- Time: 14.00 – 15.30
 Activity: Nurses IX: Joint session Nurses and Physicians: Children and young people - Giving consent for clinical trials
 Chair: P. Byron, Canada & A. Glaser, U.K.
 Location: Hall A
- Time: 16.30 – 18.00
 Activity: Nöllenburg Prize session
 Chair: H. Kovar, Austria & T. Triche, Canada
 Location: Hall A & B
- Time: 18.00 – 19.00
 Activity: SIOP Closing Ceremony

Monday, October 6th

No specific Survivors program. Parents and Survivors are always welcome to visit other sessions. The following sessions could be of interest for parents and survivors;

- Time: 08.30 – 10.00
 Activity: Nurses VI: Supportive care and symptom management.
 Chair: N. Langeveld, Netherlands & TBA
 Location: Hall A
- Time: 14.00 – 15.30
 Activity: International Working Group Teenage and Young Adults
 Chair: T. Eden, U.K. & R. Barr, Canada
 Location: Room 1
- Time: 14.00 – 15.30
 Activity: Nurses IX: Joint session Nurses and Physicians: Children and young people - Giving consent for clinical trials
 Chair: P. Byron, Canada & M. Stevens, U.K.
 Location: Hall A
- Time: 16.30 – 18.00
 Activity: Nöllenburg Prize session
 Chair: H. Kovar, Austria & T. Triche, Canada
 Location: Hall A & B
- Time: 18.00 – 19.00
 Activity: SIOP Closing Ceremony