

## 7<sup>th</sup> CCI Europe Regional Conference - Outcome Report

22. – 24. April 2016 (Belgrade, Serbia)

### Main hot topic: European Standards of Care

*Because every child and adolescent with cancer – regardless of financial or social class, race or native origin – deserves access to the best possible treatment and medical care.*



## Friday, 22<sup>nd</sup> April 2016 - Kickoff

This year we took a different approach as to how to start our conference. We wanted to give everyone, especially people attending a CCI European meeting for the first time, the opportunity to really understand CCI Europe. Therefore our first session involved giving an introduction to CCI Europe; who we are and what we do. Luisa Basset and Anita Kienesberger provided the background information about CCI and then Frédéric Arnold was able to present the fairytale story between CCI Europe and SIOPE as to how our relationship started. This was very well received among the audience.

Ensuing Olga Kozhaeva (SIOPE) from Belgium, Patty Brower from the Netherlands and Gerlind Bode from Germany and Aimilia Tsirou from Greece gave a short explanation to current EU projects that CCI Europe is involved in.

After the introduction session we had the official opening of the conference. Our hosts, Irina Ban & Vladimir Radulovic of the Serbian Childhood Cancer Network gave us a very warm welcome as well as an overview as to how their network in Serbia is organized. We had the honor of listening to H.E. Mr Michael Davenport from the EU and Zlatibor Lončar, from the Ministry of Health in Serbia. We also listened to Dragana Vujić, Head of BMU, giving a short overview of her work.

Luisa Basset also organized a special introduction recognizing what countries and organizations were attending the conference. This gave the opportunity for everyone to stand up once their country was called up. We had nearly 30 countries and more than 100 people participating from Europe.

Unfortunately Carmen, CCI chair, was unable to come but sent us a welcome message which was read on her behalf.

After a short coffee break it was time to start our parallel training session. This year we decided to let the audience decide which presentation to listen to. One of the groups was run by Maren Bösel from Germany. She organized a mentoring workshop for survivors, with focus on how different groups are organized, the types of activities they organize and how peer support is working in their own countries. It was a great opportunity to gather new ideas and share their experiences with each other.

The other session was prepared by Anne Goeres from Luxembourg. She gave valuable information about what our member organizations should think about regarding Fundraising and Public Relations. There will soon be a fundraising tool available on the CCI website.

This year we also organized a Market Place where everyone attending the conference had the possibility to present their own organization. This was a great opportunity to get to know each other.

We ended the evening with a nice dinner at the hotel.

## Saturday, 23<sup>rd</sup> April 2016 – European Standards of Care and Long-Term Follow-Up

Saturday was filled with a variety of presentations, but the main theme was European Standards of Care. We started the morning with 6 presentations of different member projects.

Session European Standards of Care - Member projects	CHAIR: Vladimir Radulović
Fertility preservation for children diagnosed with cancer	Nicole Scobie
Project "Little light of hope"	Ana Radunić; Mihael Severinac
The first <b>symposium on late-effects for Survivors</b> in Austria	Zuzana Tomasikova
<b>Create Your Future:</b> Career Counselling for Childhood Cancer Survivors	Jennifer Ziegler
<b>Child friendly approach</b> at the haemato-oncology ward of the Mother and Child Health Care Institute of Serbia	Dragana Nikolić
<b>The RB World App</b> - connecting retinoblastoma Survivors worldwide	Monika König

After the coffee break we listened to Dr. Gilles Vassal, ex SIOPE President, and Lejla Kamerić, a parent from Bosnia and Herzegovina, giving a short introduction to the European Standards of Care and the 7 objectives of the European Cancer Plan. It is widely recognized as a reference document to evaluate progress in drug development, treatment and care in the various paediatric cancer treatment centers all over the continent. The Standards of Care suggest the ideal requirements for every center specialized in the treatment of children with cancer.

Olga Kozhaeva from SIOPE talked about the progress within the EU project ExPo-r-Net, breaking border barriers between countries. Anita Kienesberger presented first results of the survey "European Standards of Care: Parents' and Patients' Organizations' point of view regarding discrepancies in Europe".

Besides there were short presentations with "best practices" in regard to European Standards of Care from 3 countries: Irina Ban, a parent from Serbia, Holly Wattwil, a parent from Sweden and Marianne Naafs-Wilstra, a parent from the Netherlands. It is safe to say that there is still much work to be done so that all children in Europe will receive the same standard of care, no matter what country they live in.

In the afternoon session we once again organized parallel sessions. The audience could choose between a workshop regarding Parents' and Survivors' Organizations, their problems/difficulties and what type of models or good practices we could share. The other session was prepared by Filippo Buccella, Founder, Clinical Network and Scientific Research, Parent project onlus in Italy. It was titled "Parents' and Survivors' Involvement in research and drug development: The example of Duchenne Parent Project and what we can learn from it."

Afterwards our theme moved into Quality of Life and Long-Term Follow-Up. Dr. Lorna Zadavec Zalatel from Slovenia offered her views regarding late effects and showed (improvement) opportunities. We had a short panel discussion with Lorna and a few survivors.

Danielle Horton Tailor from the UK gave a short summary about the importance of Long-Term Follow-Up for the future.

Saturday in the evening the Serbian Childhood Cancer Network hosted an impressive dinner with local specialties.

## Sunday, 24<sup>th</sup> April 2016 – Drug development, U2C, RareConnect & Conference Closing

Sunday's session included 3 presentations about the importance of drug development, the movement behind Unite2Cure and online patient communities.

<b>A parent-driven global consortium for childhood cancer drug development</b>	Cesare Spadoni
<b>Unite2Cure</b> Uniting for better treatments for children and teenagers with cancer	Nicole Scobie; Christopher Copland; Anne Goeres
<b>RareConnect.org - EURORDIS online patient communities for rare diseases</b>	Igor Ban

We also had the opportunity to watch a short film about a beekeeper in the Netherlands, her mission to save bees in the Netherlands while going through cancer treatments.

We ended the conference with a short session so that CCI Europe could get feedback regarding the content of the conference to better meet the expectations at next year's conference. We also shared our plans as to how we are organizing the CCI European Regional Committee.

In addition to the beekeeper movie we played the Child4Child song "We Are One". It was a very memorable moment. Please help us keeping the song - our song - alive. Use it, share it and spread it as much as you like without any cost.

**Keep the Song „We Are One” alive! Like it & share it:**



<http://youtu.be/PBzuYXCEDis>

We would like to take this opportunity to thank the Serbian Childhood Cancer Network for their wonderful hospitality. It was truly a great pleasure to visit Belgrade.

Angelo Ricci from Fiagop Onlus showed us a short movie from Rome. We are now looking forward to our next conference in 2017 which will take place in Italy. We hope to meet you there!

*Warm Regards,*

*Luisa Basset, Lejla Kamerić, Anita Kienesberger, Holly Wattwil, Aimilia Tsirou, Frédéric Arnold, Peter Lack*