



**E-Blast**  
February 2015

**ExPO-r-Net showcased at the  
ENCCA General Assembly & ECRC Meeting 2015**



15-16 January 2015, Brussels, Belgium



ExPO-r-Net Project was presented at the recent European Network for Cancer Research in Children and Adolescents ([ENCCA](#)) General Assembly & European Clinical Research Council ([ECRC](#)) meeting in Brussels. Prof Ruth Ladenstein – Project Coordinator for both ENCCA and ExPO-r-Net – outlined the project aims and background.

Based on the recent the EU Cross-border Healthcare Directive and the European Union's commitment to create European Reference Networks, the project team is in the ideal situation to interact with the ECRC stakeholder community as previously identified by SIOPE and ENCCA. The close collaboration will facilitate to identify in a real bottom up process the pre-existing collaborative structures within European Clinical Trial Groups and create in a common effort a visible Paediatric Oncology European Reference Network. This will be a major activity over the next two years.

Logistics and technical solutions for cross-boarder paediatric oncology tumour boards, efforts to raise standards of care, the next level development of the [Survivorship Passport](#) as well as the focus on the very rare tumour entities will certainly help to increase the assets of the paediatric oncology community in Europe.

**More information:**

- [ENCCA website](#)
- [ExPO-r-Net website](#)

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International Childhood  
Cancer Awareness Day



## **Successful International Childhood Cancer Awareness Day on Data Protection**

ExPO-r-Net Coordinator Prof Ruth Ladenstein provided invaluable leadership to SIOPE's International Childhood Cancer Day event 2015, dedicated this year to Data Protection.

On 3<sup>rd</sup> February 2015, more than 80 participants from all over Europe debated the projected consequences of the new EU Data Protection Regulation on childhood cancer research. The SIOPE event '[Balancing Personal Data Protection and Research Progress: The Case of Childhood Cancer](#)' took place at the European Parliament in Brussels, giving a unique opportunity for all relevant stakeholders to provide their perspectives on this controversial subject.

Hosted and chaired by MEP Glenis Willmott, a long-lasting supporter of SIOPE, the event gave visibility to the entire European childhood cancer community, deeply concerned by the fact that the proposed EU Data Protection Regulation – whilst aiming to protect patients – may unintentionally hamper biomedical research for children or prevent it altogether.

On this occasion, childhood cancer survivors and parents, healthcare professionals and representatives from the European institutions called for a harmonised Data Protection Regulation under EU legislation without Member State exemptions, to avoid fragmentation and to enable continued progress in the fight against cancer.

Prof Ruth Ladenstein has been key in driving the programme of this important event and provided priceless support in raising awareness on the topic of Data Protection – key for SIOPE's agenda.



### **More information:**

- [SIOPE International Childhood Cancer Awareness Day \(ICCD 2015\) website](#)



ExPO-r-Net Questionnaire Front Line

ExPO-r-Net Questionnaire

## **Results from the ExPO-r-Net Questionnaires**

Project Coordinator Prof Ruth Ladenstein illustrated the results from the two ExPO-r-Net questionnaires which have been circulated to all members and Chairs of European Clinical Trials groups:

1. Questionnaire on front line settings
2. Questionnaire on relapse settings.

Fourteen (14) experts from all over Europe answered the **questionnaire on front line settings,**

while the **questionnaire on relapse settings** received a total of 6 answers. Respondents provided answers based on respective fields of expertise, including disease-related subjects. The questionnaire responses received show that the majority of Clinical Trials groups are registered in public trial registries, are willing to provide the clinical trial synopsis and/or protocol(s) for reference to ExPO-r-Net, and can share information on the potential referral reference sites already in place. The answers also provide useful information concerning standard treatment recommendations, guidelines, biological markers, diagnostic tests, imaging investigations, surgical interventions, reference sites for review of pathological material, and eligibility for elective Cross Border Health Care (CBHC) referral of patients.

**More information:**

- [Link to ExPO-r-Net Questionnaire on Front Line Settings](#)
- [Link to ExPO-r-Net Questionnaire on Relapse Settings](#)



**ExPO-r-Net 3<sup>rd</sup> Biannual Meeting**  
**5-6 March 2015**

The ExPO-r-Net 3rd Biannual Meeting will take place in Padova (Italy) next 5-6 March 2015. ExPO-r-Net WP 8 leader Prof Gianni Bisogno will host the meeting, which will start with a dedicated Workshop on Very Rare Tumours on Thursday, 5<sup>th</sup> March 2015 (13:00 to 18:00) followed by a visit to the Scrovegni Chapel to see the Giotto frescos. The day will conclude with a working dinner. Friday 6<sup>th</sup> March 2015 (8:30-16:00) will be devoted to the interactive ExPO-r-Net activities to monitor our progress and advance together towards building the European Reference Network for Paediatric Oncology (PO-ERN).

All project partners are kindly invited to arrive at the latest on Thursday night (6<sup>th</sup> March) and need to provide some logistical information to the meeting organisers. Please contact the Project Manager Ms Barbara Brunmair and/or Ms Silvia Sorbara **by the deadline of 20<sup>th</sup> February 2015**.

**More information**

- **Contacts:** Project Manager Ms Barbara Brunmair ([Barbara.brunmair@ccri.at](mailto:Barbara.brunmair@ccri.at)) and Ms Silvia Sorbara ([silvia.sorbara@sanita.padova.it](mailto:silvia.sorbara@sanita.padova.it))



**Second European Reference Networks**  
**Conference & other events relevant for**  
**ExPO-r-Net**

Following the 1st conference launching the ERNs in Brussels on 23<sup>rd</sup> June 2014, the second European Reference Networks Conference will take place in Portugal this year. The date will be officially confirmed and communicated shortly.

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## Other events

The SIOPE Office is currently in the process of ensuring the promotional presence of ExPO-r-Net and a dedicated meeting at the upcoming European Cancer Congress (25-29 September 2015, Vienna, Austria) and the SIOP Congress (8-11 October 2015, Cape Town, South Africa).

## **More information**

- [First European Reference Networks Conference](#)
- [European Cancer Congress 2015](#)
- [SIOP Congress 2015](#)

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***Please do not hesitate to widely disseminate to interested colleagues.***

For more information, please contact [expornet@ccri.at](mailto:expornet@ccri.at) or [office@siope.eu](mailto:office@siope.eu).



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