



## ***ERN Call: Paediatric Oncology Community Applies***

The last three months have been a busy and exciting time for the ExPO-r-Net community, as we have been preparing the Paediatric Oncology application in response to the call for European Reference Networks (ERNs) launched by the European Commission on 16 March 2016.

The Paediatric Oncology ERN application is now submitted according to the deadline of 21 June 2016, and we eagerly await news from the assessment process. Approved ERNs are expected to be launched in early 2017.

ExPO-r-Net partners are delighted that the European Commission recognised paediatric oncology as a stand-alone priority area in the field of rare cancers, which enabled us to apply as a distinct ERN for childhood cancers.

Much work and dedication went into the application process, tirelessly led by ExPO-r-Net Coordinator and SIOPE Board Member Prof. Ruth Ladenstein, CCRI, and Barbara Brunmair, ExPO-r-Net Project Manager, CCRI.

Thus, CCRI partners attended the European Commission Information Day on the ERN call on 7 April 2016 in Brussels, which provided instrumental information for the application. Active dialogue took place with National Societies of Paediatric Haemato-Oncology (NaPHOS) and European Clinical Trial Groups (ECTGs) to streamline the application and draw a list of participating centres. (Centres can still join established ERNs at a later stage.)

Although the original intention of ExPO-r-Net was to concentrate on few rare paediatric cancer indications at first, the resulting PaedOnc ERN application has a broader scope and includes other types of childhood cancers such as leukaemia.

The PaedOnc ERN, if approved, is set to enable healthcare providers and patients to locate highly specialised cross-border healthcare (CBHC) and expert advice more easily. It also promises to foster twinning structures for identified centres in lower income European countries to reduce inequalities and provide a basis for negotiating compensation schemes for CBHC. For childhood cancer healthcare professionals already actively engaged in cross-border

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expertise-sharing, the PaedOnc ERN would formalise existing structures and practices and take highly specialised healthcare and research to the next level.

The ExPO-r-Net community looks forward to continue delivering on the project commitments while awaiting the results of the real-life ERN call – a truly promising opportunity for a brighter future for children and adolescents with cancers across Europe.

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## *Spotlight on Patients' Involvement*

«Because all children deserve the best treatment, no matter where they live»

### **Elected ePAG representatives for the paediatric cancer ERN**

EURORDIS (Rare Diseases Europe) led the process of setting up dedicated [Patient Advocacy Groups \(E-PAGs\)](#) for each future ERN to facilitate patient involvement therein.

Following the invitation to patient organisations to express their interest and the subsequent elections, the ExPO-r-Net community welcomes our Childhood Cancer International Europe partners as representatives in the Paediatric Oncology ePAG:

- **Anita Kienesberger**, Austrian Childhood Cancer Organization (Österreichische Kinder-Krebs-Hilfe)
- **Luisa Basset**, Federación Española de Padres de Niños con Cáncer (FEPNC)
- **Lejla Kamerić**, Heart for kids with cancer in FBiH (Srce za djecu koja boluju od raka u FBiH)

#### **More information:**

- [All ePAGs representatives](#)
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## *ExPO-r-Net profiled*

### **CCI Regional Europe Meeting**

On 22-24 April 2016 in Belgrade, Serbia, our partners from the European Committee of [Childhood Cancer International](#) Europe held the annual Conference of the European region, gathering enthusiastic parents, patients and survivors from the region. The central theme of this year's event was the [European Standards of Care for Children with Cancer](#).

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ExPO-r-Net was presented twice at the conference, and a general introduction to the project was made in addition for CCI Europe newcomers on Day 1.

On Day 2, the spotlight was on the ExPO-r-Net Work Package 6, which is promoting high quality patient care to reduce inequalities between centres and countries based precisely on the European Standards of Care. Last but not least, ExPO-r-Net was part of the presentation on implementing the [SIOPE Long-Term Strategic Plan](#) under the Plan's Objective 4 – Equal Access.

Patients are the ultimate reason why ExPO-r-Net is working to provide a successful model of the Paediatric Oncology European Reference Network, and this was another occasion to highlight the project activities and coordinate cooperation therein.

## ERNs Action Plan meeting

On 26 April 2016 in Brussels, Belgium, Project Coordinator Prof. Ruth Ladenstein presented the ExPO-r-Net model at the 'ERNs Action Plan' meeting organised by the Organisation of European Cancer Institutes (OECI). The meeting was dedicated to exploring the ways forward in the adult rare cancer community regarding the ERN application. It was thus an occasion to showcase the ExPO-r-Net project advancement and foster mutual learning with other disease areas in oncology.

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# In Brief

## ExPO-r-Net submits 2nd interim report

The Project Coordinators thank all partners who have contributed to this important submission to [CHAFFEA](#).

## Relevant Calls under Horizon 2020

The project community is invited to consider the following calls under the Horizon2020 EU Programme:

- SC1-HCO-08-2017: Actions to bridge the divide in European health research and innovation <http://ec.europa.eu/research/participants/portal/desktop/en/opportunities/h2020/topics/3064-sc1-hco-08-2017.html> (Single stage, **Deadline:** 11 April 2017)
  - SC1-PM-20-2017: Development of new methods and measures for improved economic evaluation and efficiency measures in the health sector <http://ec.europa.eu/research/participants/portal/desktop/en/opportunities/h2020/topics/3065-sc1-pm-20-2017.html> (Single stage, **Deadline:** 11 April 2017)
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# Save the Date - Next ExeCom Meeting!

## 6th ExPO-r-Net biannual Executive Committee meeting

29 – 30 September 2016

Vienna, Austria

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## Project Acknowledgement

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## Changes in Contact/Organisation

Dear ExPO-r-Net partners, please inform us about any news from your Work Package, as well as about any change in your contact / organisation details.

Please do not hesitate to widely disseminate to interested colleagues

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