



**E-Blast**  
March 2016

## **European Commission, CHAFEA launch ERNs call**

On 16 March 2016, the long awaited EU call to establish European Reference Networks (ERNs) was [published](#) with the [deadline to apply by 21 June 2016](#).

This is the first call for ERNs published by the European Commission in line with the [EU Directive on Cross-Border Healthcare](#) and [implementing decision of 1 March 2014](#), Article 2: “*The Commission shall publish a call for interest to establish Networks within two years following the entry into force of this Decision*”.

At least ten (10) healthcare providers established in at least eight (8) EU Member States in a given field of expertise can make the application.

In practice, applications will be submitted by the ERN Coordinators, to whom individual healthcare providers that are part of those ERNs should supply the required documentation.

As a logical extension of ExPO-r-Net, participants at the latest project meeting in Lund, Sweden, agreed that Coordinator Ruth Ladenstein and her institution are best placed to make the ERN application on behalf of the Paediatric Oncology community.

Preparatory work by the Coordinator and individual health providers can already be undertaken based on the [ERN Assessment Manual and Toolbox](#) made available by the European Commission. It includes:

- Applications Checklist
- Self-assessment Forms (for Network Coordinator and Healthcare providers)
- Application Forms (for Network Coordinator and Healthcare providers)
- Sample Letter of National Endorsement for Healthcare Providers

An [Information Day](#) about the call for ERNs is organised by the European Commission and CHAFEA on 7 April 2016 in Brussels. ExPO-r-Net Coordinator Ruth Ladenstein will be attending on behalf of the Paediatric Oncology community and sharing the outcomes to prepare our application. In addition, live webstreaming will be made available for all who wish to follow the discussion.

### **Useful links:**

- [ERNs call](#) (CHAFEA website)
- [ERN Assessment Manual and Toolbox](#)
- [ERNs Info Day](#)

## **ExPO-r-Net goes to Lund – 5<sup>th</sup> ExeCom meeting**

The 5<sup>th</sup> biannual ExPO-r-Net Executive Committee (ExeCom) meeting took place on 3-4 March 2016 in Lund, Sweden.

It was warmly hosted by Lunds universitet/Lund University, Leader of Work Package 7 – ‘*Cross-border dimension of long-term follow-up: survivorship passport with crucial treatment & follow-up data*’.

### **European Commission and CHAFEA join us**

The meeting also welcomed the participation of the ExPO-r-Net Project Officer from the European Commission Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) as well as a European Commission representative by teleconference on Day 1.

The CHAFEA Officer shared strong positive messages about the ExPO-r-Net progress as evaluated by the Agency, highlighting the effective coordination and broad visibility of the project among its other achievements.

The European Commission provided an update on the legislative and operational side of the application process for the ERNs.

### **Preparing the ERN call**

The meeting enabled project partners to take stock of the progress and state of play in relation to the first calls for real-life European Reference Networks (ERNs). Through active exchange, participants succeeded to jointly define the approach for the Paediatric Oncology (PO) application. Thus, it was agreed that the ExPO-r-Net Coordinator Ruth Ladenstein and her institution, the St. Anna Children's Cancer Research Institute are in the best position to coordinate the PO-ERN application.

With input from the European Commission, the meeting also addressed Member State endorsement of healthcare providers as a condition to apply for ERNs. Such endorsement was confirmed as mandatory, and project partners are invited to obtain it by contacting their national authorities as soon as possible.

### **WP achievements**

On Day 1 of the meeting, Work Package leaders shared an overview of their key achievements:

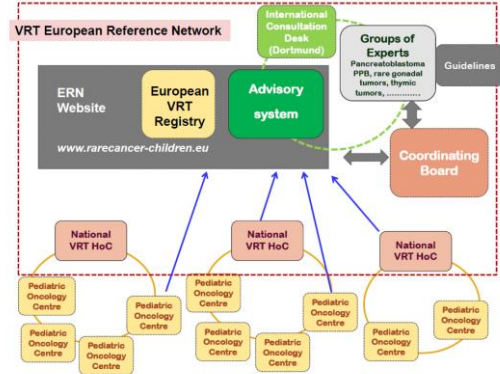
- **WP4**: The identification of reference sites is almost finalised as a result of mobilising European Clinical Trial Groups (ECTGs);
- **WP 5**: Tumour Boards have been identified in the context of interoperability and moving expertise rather than patients whenever possible;
- **WP 6**: Multiple centres in Central and Eastern Europe have completed self-assessment questionnaires to link with the PO-ERN main reference sites;
- **WP 7**: The Survivorship Passport and Guidelines, now multi-lingual, remain a key focus along with the development of the virtual multi-disciplinary platform for late complications;
- **WP 8**: A VRT network tumour board with defined working procedure has been established and an Advisory Desk opened.

## Pilot networks take shape

On both Day 1 and 2, participants discussed the progress on the specific pilot reference networks and roadmaps.

### Very Rare Tumours (VRT) Roadmap

It was concluded that, despite being different, VRTs share the same type of challenges, making their integration in a single framework an effective solution, rather than creating different networks dedicated to single VRTs.



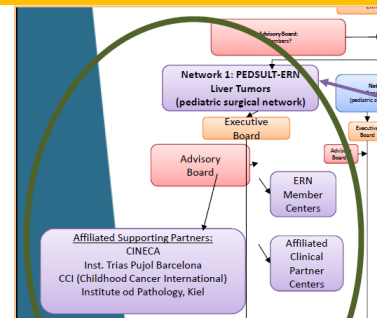
### Retinoblastoma Roadmap

In retinoblastoma, cross-border cooperation is already ongoing in a multidisciplinary manner, including a strong patients' role.



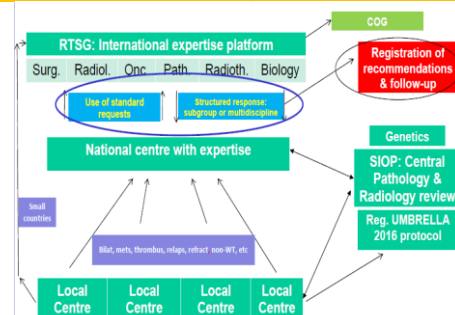
### Liver Tumours Roadmap

The extensive mapping exercise to develop the roadmap considered different factors including the number of procedures performed per centre and their level of complexity.



### Wilms / Renal Tumours Roadmap

The main issues to be addressed by the roadmap include a centralised pathology and radiology review and analyses/storage of tumour cells, blood and urine.



## **Spotlight on Patients' involvement**

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

The patient roadmap is a central aspect of ExPO-r-Net. Indeed, families should be aware of exactly how to reach the best available care for the project to be effective in its mission of reducing inequalities in childhood cancer survival across Europe.

### **Parents and Patients in ExPO-r-Net: CCI International**

Cooperation with patients and families is embedded in ExPO-r-Net through the involvement of [Childhood Cancer International \(CCI\)](#). CCI has been actively involved since the beginning and is indeed a long-term and valued partner in the community, including through a Memorandum of Understanding with SIOPE.

Through CCI, parents and patients take part in ExPO-r-Net activities and provide essential input on their real needs.

Thus, parents will be participating in site visits to get further acquainted with candidate-centres in Central and Eastern Europe, pre-identified based on the [European Standards of Care for Children with Cancer](#) as potential PO-ERN partners.

At the ExPO-r-Net project meeting in Lund, Sweden, CCI shared an important message - Parents and patient groups in the different EU Member States should cooperate increasingly more to be able to share information in an organised way and benefit fully from the European Reference Networks.



It was also the occasion for CCI to share an inspirational message and new video and musical campaign – <http://child4child.com/>

Spread the word about this great initiative – anyone can join!

### **EURORDIS**

EURORDIS (Rare Disease Europe) represents rare disease patients at European level. The organisation engages regularly with the paediatric oncology community, including through SIOPE.

EURORDIS is currently undertaking a number of informative and mobilisation activities to ensure that patients can fruitfully engage with the European Reference Networks.

In particular, patient organisations across Europe are invited to take part in the [EURORDIS Patient Advocacy Groups \(E-PAGs\)](#). A dedicated E-PAG will be aligned to each of the future European Reference Networks (ERNs). The purpose is to facilitate a democratic process of patient involvement at different levels of ERN implementation and decision-making.

EURORDIS also organises [webinars](#) on ERN topics.

#### **For more information:**

- [EURORDIS ERN activities](#)

## **HoNCAB Final Conference 18th February 2016**

On 18 February 2016, SIOPE represented ExPO-r-Net at the [pilot network of hospitals related to payment of care for cross border patients \(HoNCAB\)](#) final conference.

The project had started in September 2012 under the 2<sup>nd</sup> EU Health Programme. It was tasked with linking healthcare providers to exchange experiences and best practice on dealing with patients from other EU Member States. Particular consideration was given to reimbursement issues.

Although not addressing ERNs, the project can be relevant for ExPO-r-Net partners in terms of lessons learned on the practical implications of cross-border treatment.

Following the project conclusion, the involved hospitals intend to continue cooperation.

### **For more information:**

- [HoNCAB Recommendations](#) (draft)
- [HonCAB Handbook for Hospitals](#) (draft)
- [HonCAB website](#)

## **ExPO-r-Net profiled**

### **CHAFEA brochure**

CHAFEA regularly produces brochures showcasing the projects supported under the EU Health Programme. ExPO-r-Net was contacted to feature in a next edition dedicated to rare diseases. Having provided information about our key initiatives and achievements, we look forward to seeing the outcome and sharing it broadly.

### **SIOPE Long-Term Strategy Launch at the European Parliament**



On November 2015, SIOPE launched its Strategic Plan – the [European Cancer Plan for Children and Adolescents](#), at the European Parliament in Brussels. Organised in cooperation with the [MAC – Members of the European Parliament Against Cancer](#), the event attracted some 100 participants and was a great success.

ExPO-r-Net is an integral part of the SIOPE Strategic Plan under its Objective 4 – Equal Access. At the launch event, Ruth Ladenstein presented the project, and information material was made available to all participants.

### **World Cancer Day activities**

The first week of February saw SIOPE and ExPO-r-Net at the European Parliament in Strasbourg, France. In cooperation with other cancer societies, it was the occasion to raise awareness on paediatric cancer and our activities to promote more and better cure.

The ExPO-r-Net stand was visited by numerous MEPs as well as the European Commissioner for Health Vytenis Andriukaitis.



## Future Events: Save the Date

- **European Commission ERN calls Info Day**  
7 April 2016 ([live webstreaming available](#))

## Project Acknowledgement

Please remember that ExPO-r-Net publications, posters, presentations, web pages and should:

1. Display the following EU logo (available [here](#))
2. Display the ExPO-r-Net logo (available [here](#))
3. Include the following formula:



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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.***

Contact [expornet@ccri.at](mailto:expornet@ccri.at) or [office@siope.eu](mailto:office@siope.eu) for more information.



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