

June-July 2017 edition



E-Blast

## ERN PaedCan: Yes, We Made It!



During the ERN Conference in Vilnius (Lithuania) last 9-10 March 2017, the **European Reference Network on Paediatric Cancer– ERN PaedCan has been officially approved**. This outstanding result has been achievable thanks to the great team effort and the strong commitment of all ExPO-r-Net partners and invaluable contribution of the project Coordinator Prof. Ruth Ladenstein and her team at the CCRI, in particular Melanie Brunhofer MSc, Barbara Brunmair PhD, and Zoltan Dobai, MSc, who managed to consolidate the preconditions for this multinational network.

In concrete words, implementing this ERN means a step forward to implement new ways of

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communications and in particular the establishment of virtual tumour boards across European Clinical Trial Groups in the years to come by implementing the European Commissions offer of the Clinical Patient Management System (CPMS) as a tool to run virtual tumour boards free of charge. By providing a clear roadmap to sites specialised in certain rare interventions necessary in complex childhood cancer cases will help to overcome gradually current inequalities in Europe.

Partners in the [ExPO-r-Net project](#) are confident that this ERN will facilitate the provision of highly specialised, accessible and cost-effective cross-border healthcare to those childhood cancer patients in Europe with particularly demanding and complex disease presentations and in need for special therapeutic advice and approaches. Over the past three years, the structure for a clear framework for the exchange of information among more than 60 paediatric oncology centres has been created to enable national health systems to cooperate in the best interest of patients.

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## ERN PaedCan Kick-Off Meeting & Final ExPO-r-Net Meeting



***29-30 June 2017, Brussels, BE***

To discuss the final outcomes of this multiannual project, Expo-r-Net members and collaborative partners and ERN PaedCan members were invited to participate at the **ERN PaedCan official kick-off meeting and the Final meeting of the ExPO-r-Net Project, 29-30 June 2017 at the Renaissance Hotel in Brussels, Belgium.**

The meeting started on 29 June with a meeting of the SIOPE Clinical Research Council for paediatric and adolescent oncology (SIOPE CRC), and continued with the official ERN PaedCan Kick-off Meeting **combined with the final meeting of the [ExPO-r-Net project](#).**

The meeting benefited from a special contribution of high level EU policy makers such as **EU Health Commissioner Vytenis Andriukaitis**, who provided a video message as part of the Opening Session; and delegates from DG SANTE including Director-General **Xavier Prats Monné**, Policy Officer **Enrique Terol**, Head of Unit for Information Systems **Herman Brand**, and Head of Unit for Cross-Border Healthcare&eHealth **Tapani Piha**.

More information on the **meeting and the agenda** here: [www.expornet.eu](http://www.expornet.eu).

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# 7th ExPO-r-Net Biannual ExeCom Meeting

*30-31 March 2017, Padua, IT*



On 30-31 March 2017, the ExPO-r-Net consortium met in Padua for the 7th ExPO-r-Net biannual meeting of the Executive Committee (ExeCom). The first good news was the announcement of the **ExPO-r-Net project extension of about 6 months** until the end of August 2017. In her opening speech, Prof. Ruth Ladenstein, CCRI (Coordinator of [ExPO-r-Net](#) and the [ERN PaedCan](#)) informed the consortium about the fact that all **ExPO-r-Net activities will be embedded into the ERN PaedCan** after its official finalization.

Overall, the meeting focused on project developments and activities to be carried out before the final meeting of the project in June 2017, and most importantly addressed the following points:

1. **Project Dissemination** (Samira Essiaf, CEO SIOPE): Communication material was distributed in over 30 meetings in the last 3 years (ExPO-r-Net E-Blast, SIOPE newsletter, ExPO-r-Net public website and intranet, flyers, banners, etc.) and statistics showed that an increasing number of people wanted to obtain some information about the project over the past years;
  2. **Common Vision of CINECA and AIT** (Günter Schreier, AIT and Marisa de Rosa, CINECA): CINECA and AIT are collaborating in building an interoperable 'Virtual Consultation System' platform.. The 'Virtual Tumour Board' (VTB) was illustrated during the meeting via a 'Live Demonstration';
  3. **Very Rare Tumours** (Gianni Bisogno, AOPD): A common proposal for the Very Rare Tumour network across Europe was submitted and a number of new publications with guidelines for VRT entities were presented at the meeting as an consensus output.
  4. **Parents and Patients involvement** (Anita Kienesberger, CCI Europe): Parents and Patients organisations were actively involved in on-site audits in Eastern European countries, organized by Jerzy Kowalczyk from the University of Lublin, Poland;
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**Evaluation- progress update and action points** (Pamela Kearns, University of Birmingham): Economic analysis of VTB and IT systems are currently undertaken by Prof. Pamela Kearns and Richard Sullivan.

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## Survivorship Passport: Latest Developments

On the occasion of the ExPO-r-Net ExeCom Meeting in Padua, Italy, Riccardo Haupt, Survivorship Passport Coordinator from the Gaslini Institute of Genoa, commented on the latest developments in this important initiative.



The Survivorship Passport (SurPass) will provide childhood cancer survivors and clinicians with an easy access to a treatment summary and personalised recommendations, to ensure that potential side effects can be recognised quickly and be accurately diagnosed and treated. Its **prototype** has been finalised by tapping into the existing European resources, infrastructures and study groups. SIOPE and some ExPO-r-Net partners actively contributed to its development by cross-checking the accuracy and user-friendliness of the information available for the future online platform, and by helping in the design of the SurPass recommendation brochures.

The SurPass initiative has also been included in the [EU Joint Action on Rare Cancers \(JARC\)](#), which will tackle the existing lack of networking between countries and clinics across Europe and inequalities of access to follow-up care. Within the JARC initiative, the SurPass guidelines on models of healthcare for survivors of childhood cancers developed by PanCare partners will be further consolidated.

Most importantly, the SurPass prototype is starting to be tested and the aim is to integrate the SurPass into the EU Member States' National Cancer Plans. SIOPE and ExPO-r-Net partners have been liaising with Health Ministries to ensure that this model will be effectively adopted and introduced into national healthcare systems in Europe. So far, it has been included in 2015 in the 5-years' Austrian cancer plan and in September 2016 'Childhood Cancer Switzerland' – an organisation regrouping healthcare specialists, families, and survivors of childhood cancer – agreed to start introducing of the "Survivorship Passport" in all Swiss paediatric hospitals. Belgian authorities also showed a sheer interest in this initiative.

A peculiar aspect of the SurPass initiative has been the effective exchange of information and **collaboration with parent and survivor organisations**, which allowed to better understand their needs and increase general awareness about survivorship issues. The SurPass was also included in one of the seven objectives of the [SIOPE Strategic Plan](#), document which received a considerable endorsement from representatives from all the European paediatric oncology community.

The SurPass represents a potentially effective **model to improve the quality of life of former childhood cancer patients** by better monitoring their health, supporting them in their 'transition' into adult healthcare, and empowering them to be responsible for their own well-being. This innovative solution can potentially increase the capacity to fully respond to the needs of European survivors, and result in a more appropriate and cost-effective use of healthcare systems' resources.

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## ERN PaedCan Website, Logo, List of Members



The ERN PaedCan **website** is under development, accessible via the European Commission online portal for ERNs or through the direct website link: [paedcan.ern-net.eu/](http://paedcan.ern-net.eu/).

Similarly, the ERN PaedCan **logo** will be provided to all ERN PaedCan members, once the sublicensing agreement which all partners are requested to sign is returned to the Project Management Team ([ernpaedcan@ccri.at](mailto:ernpaedcan@ccri.at)). The contracts were sent to the partners and are now collected by the Network Management Team.

After having received all signed agreements, partners will be allowed to use the logo and informed about the policy on when and how to correctly use it.

The ERN PaedCan Project Management Team also invites project partners to check the correctness of the contact information provided in the **list of contacts of all the members of the ERN PaedCan network**, which was circulated earlier this year as an Excel sheet (for more information, please ask [ernpaedcan@ccri.at](mailto:ernpaedcan@ccri.at)).

Finally, project partners can find all relevant **information about cross-border healthcare** (e.g. a list of national contact points, reports from the last cross-border conferences, videos etc.) on the dedicated webpage prepared by European Commission's DG SANTE at this link: [http://ec.europa.eu/health/cross\\_border\\_care/policy\\_en](http://ec.europa.eu/health/cross_border_care/policy_en)

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Co-funded by  
the Health Programme  
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