



From

ExPO-r-Net

European Expert Paediatric Oncology Reference Network for
Diagnostics and Treatment

to

ERN-PaedCan

European Reference Network
on Paediatric Cancer



ERN Co-Ordinator:

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ERN Dissemination:

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Need for the ERN PaedCan

- **Paediatric Cancer is rare** and comes in multiple subtypes. With 20 000 children newly diagnosed with cancer across Europe and 6000 paediatric patients dying each year, it remains the **leading cause of death from disease for children older than 1 year of age.**
- Average survival rates have improved in recent decades, however for some conditions the outcomes remain very poor.
- **Significant inequalities in survival rates are a challenge** in Europe with worse outcomes of about 20% in Eastern Europe.

ERN-PaedCan Mission

ERN-PAEDCAN aims to provide paramount requirements for ‘Cross-border healthcare’:

- **Provision of high quality healthcare to children with cancer in a Member State other than the Member State of affiliation.**
- **Identification of those children and young people with cancer conditions requiring a particular concentration of resources and expertise (especially when there are only a few cases and the expertise for certain cancer diagnoses is rare).**





From ExPO-r-Net to ERN-PaedCan

Future Key Benefits



- **A European Childhood Cancer Roadmap:** Guidance Document for Health Care Providers to direct affected families to specialized centres.
- **Possibility to be treated at home or abroad:** Mechanisms to facilitate movement of information and knowledge rather than patients whenever possible. (IHE based **Virtual Tumour Boards (VTB)** and **Case Consultation Systems (VCS)**).
- **Registries for Very Rare Tumours entities** where case numbers are too low to consider a clinical trial setting.

➤ **Elevated standards of treatment and care across Europe**

Kowalczyk et al. (Eur J Cancer 2016)





From ExPO-r-Net to ERN-PaedCan

Future Key Benefits



- **Twinning Programs and special Teaching & Training Programmes** (eLearning, movies, lectures, fellowship trainings etc.).
- **Long term follow up including patient reported outcomes and advise for childhood cancer survivors** with implementation of supporting tools (Apps) including the **Survivorship Passport** (condensed disease & treatment information linked with late effect caution recommendations).
- **Institution of a Virtual Late Effect Advisory Platform**
- **Aim to improve reimbursement arrangements between MS for medical advise and fair access to early trials for affected European families**





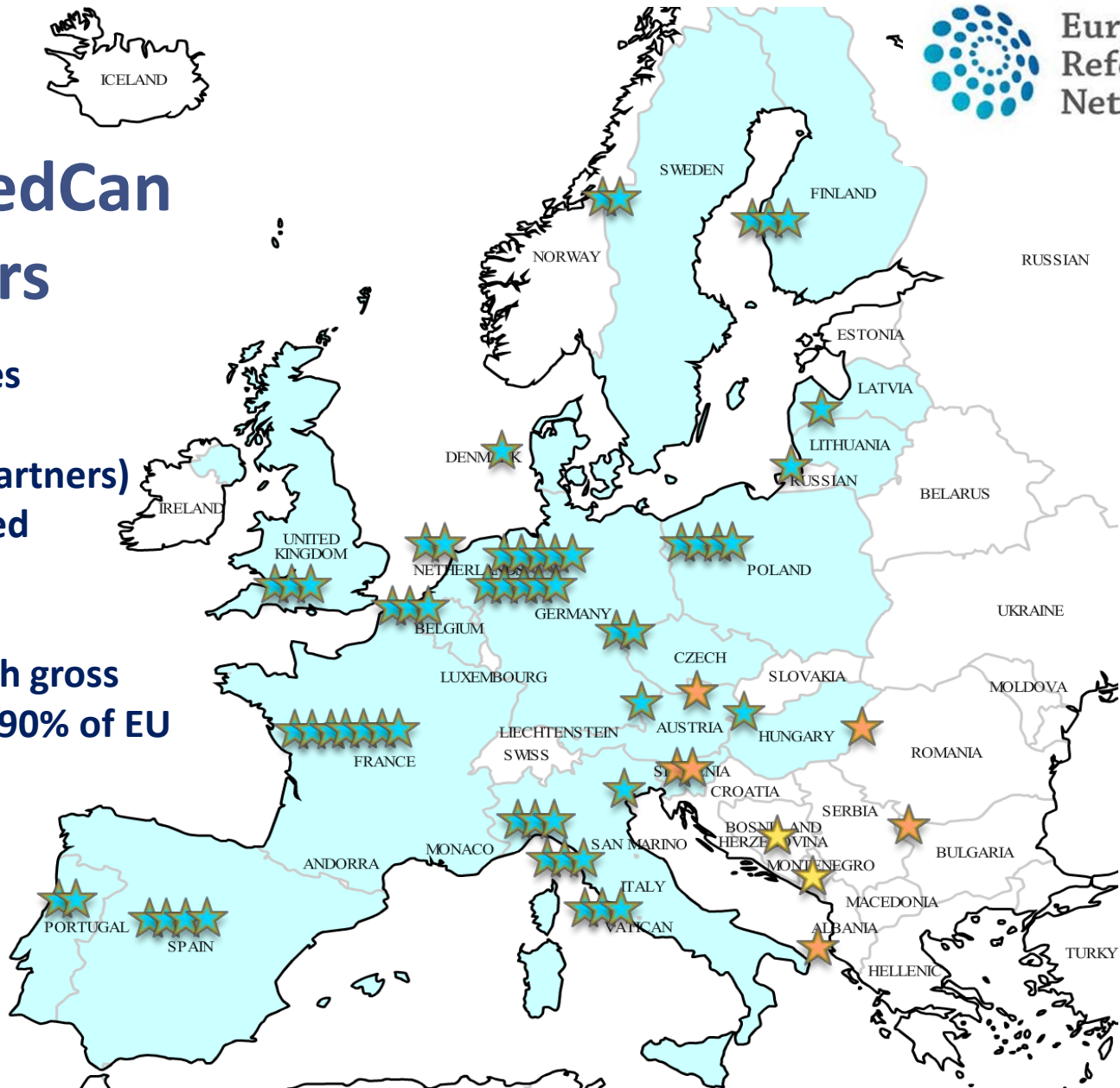
ERN-PaedCan Members

 18 EU countries

 57 HCP (full partners)

 6 HCP (affiliated partners)

28% members with gross national income <90% of EU average



16 European Clinical Trial Groups

3 Overarching Organisations

SIOPE
Brain tumour group

Brain Tumour

Germ Cell Tumours

Germ Cell Tumours

Histiocyte Society

Langerhans Cell Histiocytosis

SIOPEL
(SIOPE-Epithelial Liver Tumour Study Group)

Liver Tumours

SIOPEN
(SIOP Europe Neuroblastoma Group)

Neuroblastoma

EICNHL
(European Inter-group cooperation on childhood and adolescent Non Hodgkin)

Non-Hodgkin Lymphoma

SIOP-RTSG
(SIOP Wilms Tumour)

Renal Tumours

EpSSG
(European Paediatric Soft Tissue Sarcoma Study Group)

Soft Tissue Sarcomas

Ewing's Tumour

EURO-E.W.I.N.G.

Hodgkin's Lymphoma

EHL
(European Hodgkins Consortium, EuroNet-PHL)

Leukemias and Lymphomas

I-BFM
(The International BFM Study Group)

Myelodysplasia

EWOG-MDS

Osteosarcoma

EURAMOS

Soft Tissue Sarcomas

CWS
(Cooperative Weichteilsarkom Studiengruppe or Cooperative Soft Tissue Sarcoma StudyGroup)

Very Rare Pediatric Tumours

EXPeRT
(European Cooperative Study Group on Paediatric Rare Tumours)

EURBG
(European RetinoBlastoma Group)

Retinoblastoma

Stem Cell Transplantation

EBMT
(European Group for bone marrow and stem cell transplantation Paediatric Working Party)

New Anticancer Agents

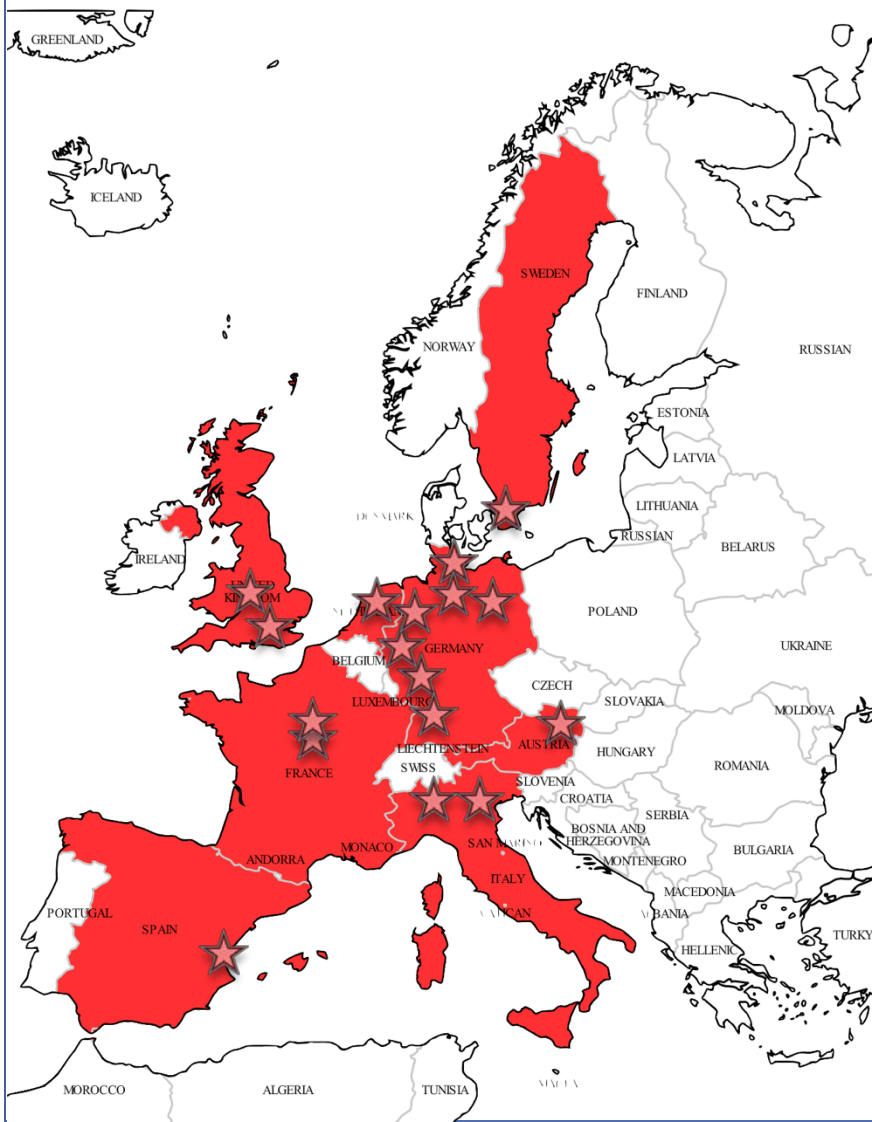
ITCC
(Innovative Therapies for Children with Cancer)

PanCare

Survivorship and Late Effects



European Clinical Trial Groups Coordinating Trial Sites = “HoCs”



| Country | Institute, Location |
|----------------|--|
| 1 Austria | St. Anna Kinderspital (SAK)/Children's Cancer Research Institute (CCRI), Vienna |
| 2 France | Institut Gustave Roussy (IGR) , Villejuf |
| 3 France | Institut Curie, Paris |
| 4 Germany | Christian-Albrechts-Universitaet zu Kiel (CAU) |
| 5 Germany | Charité Universitätsmedizin Berlin (Charité) |
| 6 Germany | Universitätsklinikum Frankfurt |
| 7 Germany | Olgahospital, Stuttgart |
| 8 Germany | University Hospital Hamburg |
| 9 Germany | University Children's Hospital, Bonn |
| 10 Germany | Universitätsklinikum Münster |
| 11 Italy | Azienda Ospedaliera di Padova (AOPD) |
| 12 Italy | Universita degli Studi di Milano-Bicocca, Ospedale San Gerardo di Monza (Biondi, Jankovic) |
| 13 Netherlands | Princes Maxima Centrum, Utrecht |
| 14 Spain | Hospital universitario La Fé, Valencia |
| 15 Sweden | Lunds universitet (ULUND), Lund |
| 16 UK | University College London (UCL, Pritchard-Jones, Wheelan) |
| 17 UK | Birmingham Children's Hospital (UOB) |



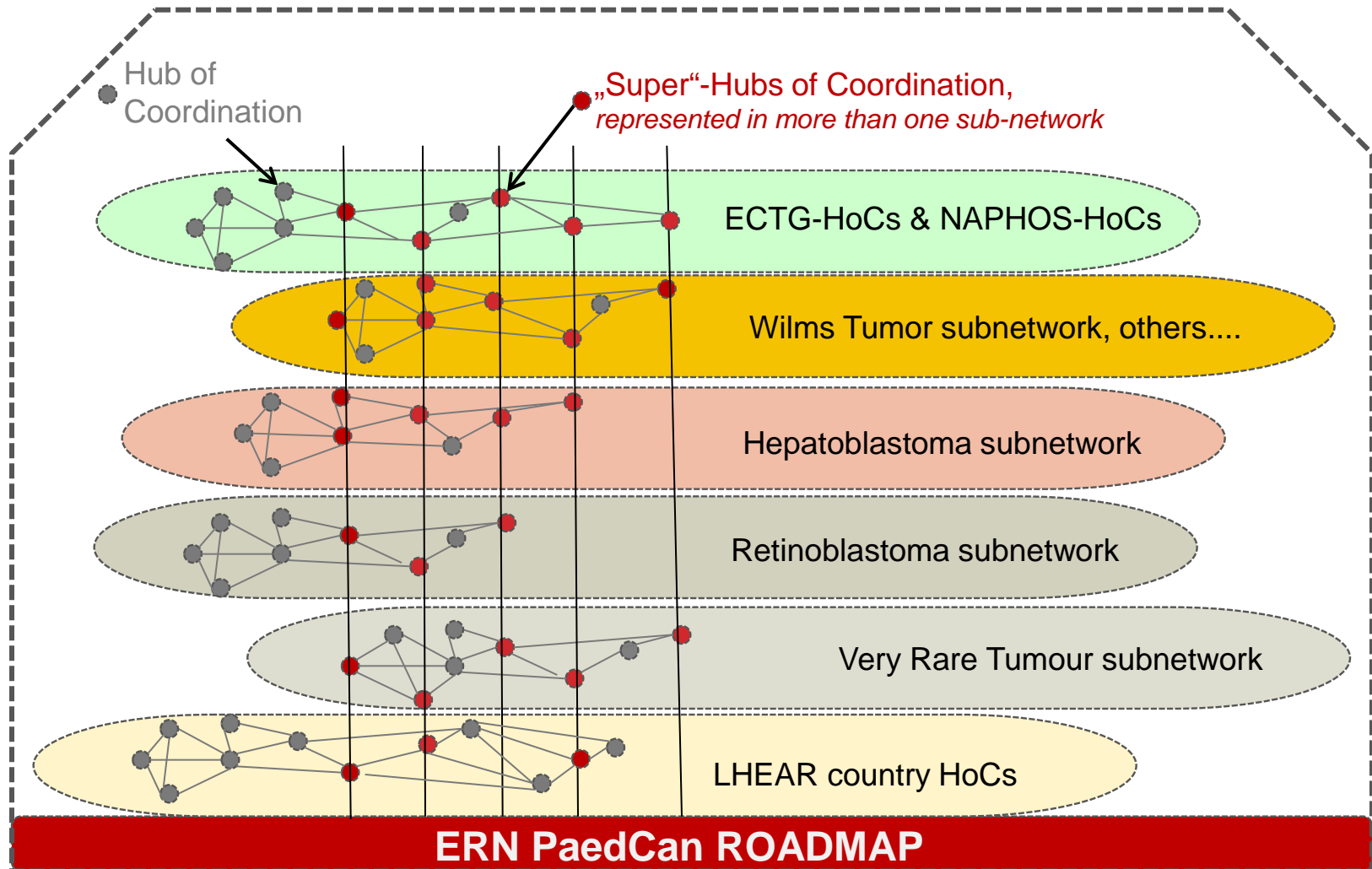
ERN-PaedCan Roadmap

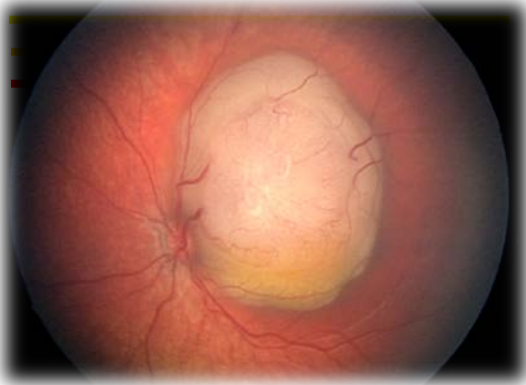
- **Identifying special therapeutic needs** of young people with cancer requiring high expertise interventions with ECTG
Examples: special surgery, radiotherapy (proton therapy, etc.)
- **Healthcare cooperation and resolving expert fragmentation**
- **Identification of European HCP ready to engage as Reference Centres**
- **Identification of European HCP offering top level expertise** for special therapeutic interventions and referrals
- **Identification of National Childhood Cancer Parent Groups** to support network activities



**Roadmap Guidance for Health Care Providers
Increased Transparency for Affected Families**

The Roadmap Strategy





Subnetwork Example I: Retinoblastoma



□ Background

- A rare malignancy of young children (10% of tumours in infants) with excellent survival rates. Implementation of vision-sparing treatments as major aim.
- **Major changes in treatment paradigms:** intra-arterial and intravitreous chemotherapy, use of pre-enucleation chemotherapy in high risk children **but without harmonized strategy**.
- Highly specialised encompassing multidisciplinary care concentrated in a few centres, but is fragmented in many EU countries with low patient accrual.
- Known centres in EU as global leaders with ability to transfer knowledge to smaller groups.



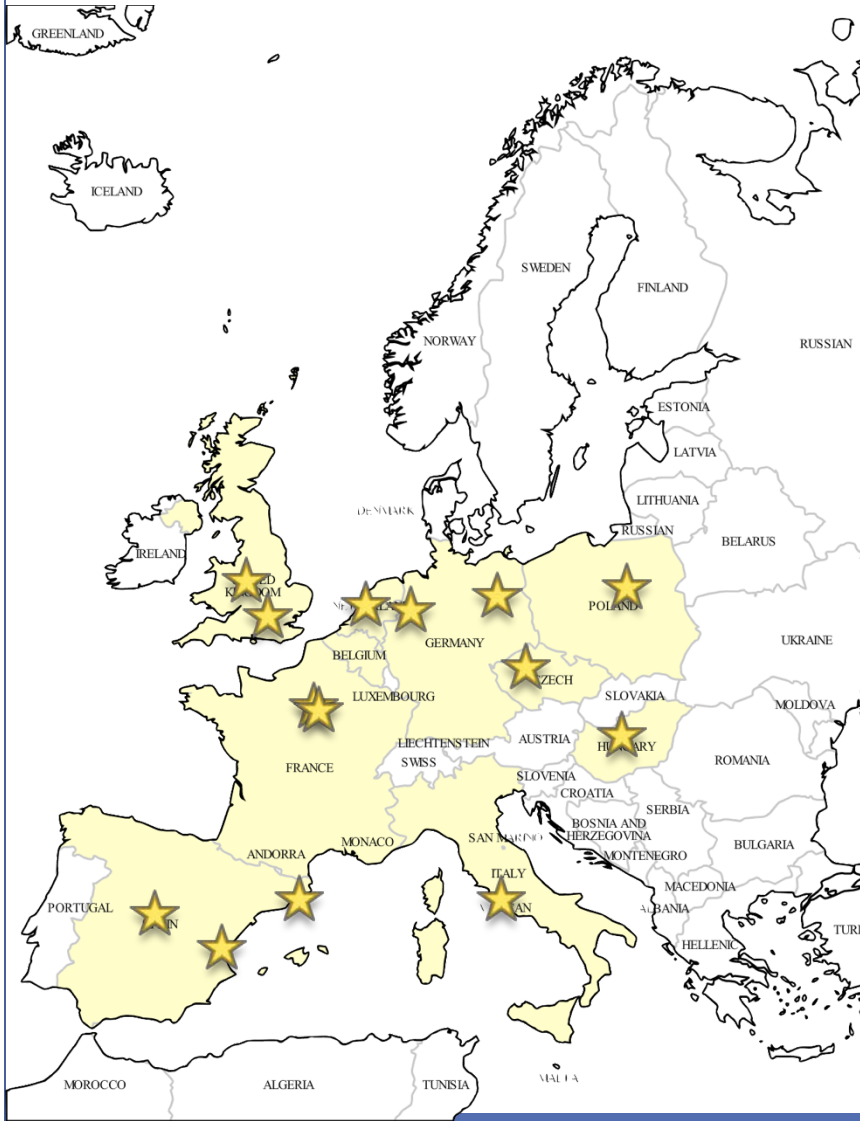
European Retinoblastoma Group: Varying Hubs of Expertise



| HoC | #Pts | Intra-arterial | Brachytherapy | Research lab | Imaging | Extraocular |
|-----------|------|----------------|---------------|--------------|---------|-------------|
| Paris | ++++ | + | +++ | +++ | +++ | +++ |
| Essen | ++++ | + | N/A | +++ | ++ | + |
| Lausanne | ++ | + | +++ | + | + | + |
| Siena | ++ | +++ | +++ | + | +++ | + |
| Barcelona | + | ++ | ++ | +++ | + | ++ |
| UK | ++ | ++ | ++ | + | + | + |
| Amsterdam | + | - | ++ | + | +++ | + |



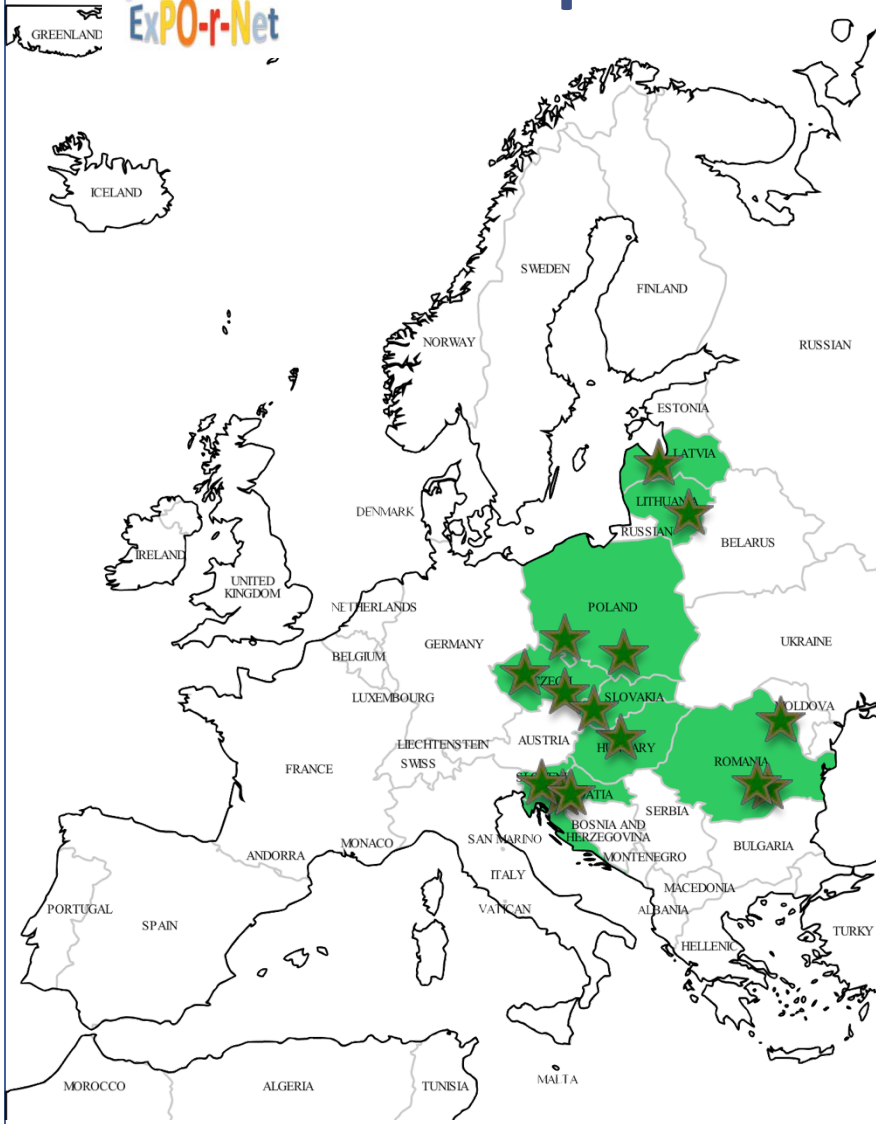
Retinoblastoma HoCs



| Country | Institute, Location |
|-------------------------|---|
| 1 Belgium | Cliniques Universitaires Saint-Luc, Brussels |
| 2 Czech Republic | Motol Children's Hospital, St. Charles University, Prague |
| 3 France | Institut Curie, Paris |
| 4 France | Fondation Rothschild, Paris |
| 5 Germany | Charité Universitätsmedizin Berlin (Charité) |
| 6 Germany | University Clinic Essen |
| 7 Hungary | Semmelweis University Budapest |
| 8 Italy | Ospedale Pediatrico Bambino Gesù, Rome |
| 9 Netherlands | VU University Medical Center, Amsterdam |
| 10 Poland | Memorial Children's Hospital, Warsaw |
| 11 Spain | Hospital universitario La Fé, Valencia |
| 12 Spain | Hospital Universitario Vall d'Hebron |
| 13 Spain | Hospital Sant Joan de Déu, Barcelona |
| 14 Spain | Hospital Carlos III (Madrid), Madrid La Paz |
| 15 UK | Birmingham Children's Hospital (UOB) |
| 16 UK | Great Ormond Street Hospital, London |



Example II: LHEAR country “HoCs”



| Country | Institute, Location |
|------------------|---------------------|
| 1 Croatia | Zagreb UHC |
| 2 Croatia | Zagreb KDBZ |
| 3 Czech Republic | Praha |
| 4 Czech Republic | Brno |
| 5 Hungary | Budapest SEMMELWEIS |
| 6 Latvia | Riga |
| 7 Lithuania | Vilnius |
| 8 Poland | Wroclaw |
| 9 Poland | Warsaw |
| 10 Poland | Cracow |
| 11 Romania | Bucharest ICF |
| 12 Romania | Bucharest JOB |
| 13 Romania | Jasi |
| 14 Slovakia | Bratislava |
| 15 Slovenia | Ljubljana |



The parents'/patients' voice within ERN PaedCan

European Patient Advisory Group (ePAG)

Mission = to unite the patients' voice and optimize patients' involvement

- **Anita Kienesberger**
Austrian childhood cancer organization
- **Luisa Basset**
La Federación Española de Padres de NIÑOS CON CÁNCER
- **Lejla Kamerić**
Heart for kids with cancer – Bosnia and Herzegovina
- Supported by **Stephanie Schremmer**
Austrian Childhood Cancer Organization





European
Reference
Networks



Childhood
Cancer
International

CCI Europe Members

- 66 Organisations
- 33 Countries

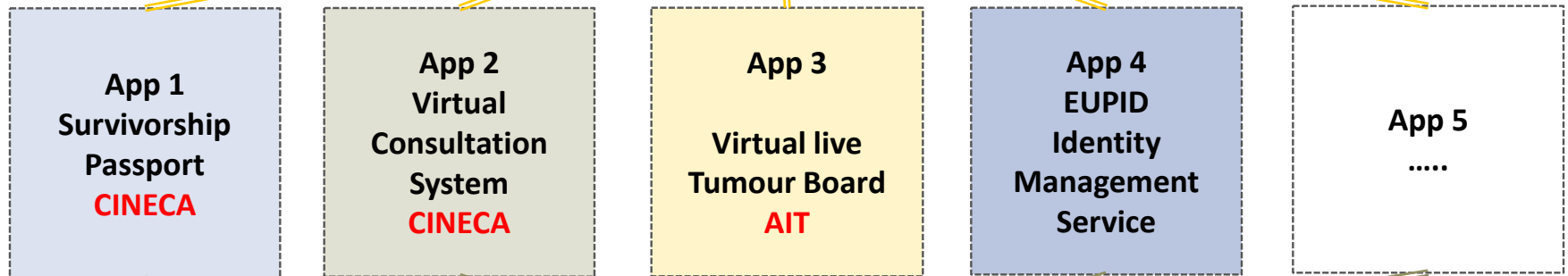


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eHealth Interoperability Architecture for ERNs

Reliable, secure, standardized and managed web/videoconferencing solution

Communication services can be used by all interoperable Apps



Interfaces to ExPO-r-Net eHealth platform services



What comes next?

Approval of personalized ERN PaedCan logos for each HCP

Meetings

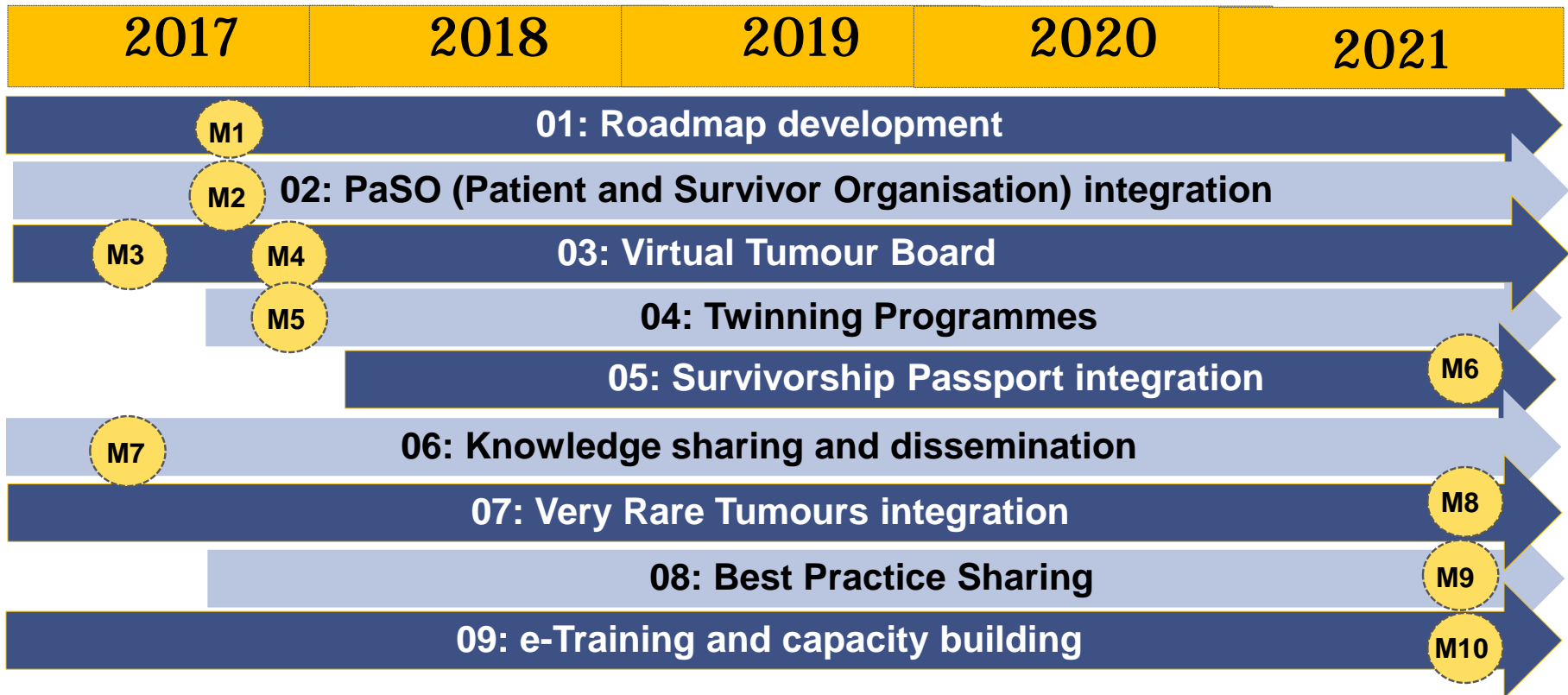
SAVE THE DATE:

ERN PaedCan kick-off meeting 29/30 June 2017

Combined with ExPO-r-Net meeting

Brussels

ERN PaedCan 5-year Implementation Plan



M1: Roadmap document
M2: PaSO contact points identified
M3: Centres integration of VTBs
M4: Monitoring VTBs

M5: Twinning network established, Final report on success of twinning programmes
M6: National SUPA integration in a least one MS
M7: Dissemination & Communication Plan
M8: Ready to use VRT-VCS implemented with an activity report in Year 5
M9: Publish best practice guidelines (1 topic/year)
M10: Fellowship training established and evaluation (Year 5)



www.siope.eu



The pilot project *European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment: 2014-2017*): funding from the European Union in the framework of the Health Programme (2008-2013), grant agreement nr. 2013 12 07.

www.expornet.eu



Thank you for helping to create a brighter future for children with cancer



Co-funded by
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EnprEMA and ERN's

A coordinators view



- ❑ ERNs deal with Rare Diseases- most of them start at paediatric age
- ❑ The therapeutic need – a cross boarder issue
- ❑ Identify the common needs (MOA) across diseases and borders
- ❑ Structured CBHC advise (Virtual Consultation Systems are key to address identified experts and sites (i.e. ERN PaedCan roadmap, proposed twinning ...)
- ❑ Improve access to treatment innovation and new drugs
- ❑ EU policy action: Requirement of widening current “S2 Form” allowing cost compensation between MS also when entering into early trials (improve accrual into important trials –academic and industry driven)
- ❑ Together we are strong – overcome actions in isolation:
ERNs – EPAC (European Patient groups - Rare Disease communities, Academia experts , industry , regulators ,



Back Up Slides

Organisational Structure

