Towards a European Reference Network in Paediatric Cancer: The Network Coordinator View
Prof. Ruth Ladenstein (CCRI, Vienna-AUSTRIA)
• ExPO-r-Net is a 3-year project to build a European Reference Network (ERN) for Paediatric Oncology.

• ExPO-r-Net aims to reduce the current inequalities in childhood cancer survival and healthcare capabilities in different EU Member States
  - Support cooperation on cross-border healthcare and mobility of patients, health-care professionals and information
  - Innovate healthcare delivery
The Paediatric Oncology European Reference Network

- will improve the standards of care across Europe
- will let children and young people with cancer benefit from high-quality, accessible and cost-effective healthcare
- http://www.expornet.eu
Childhood Cancer

- Rare Disease Definition: 1 in 2000  [www.eurordis.org](http://www.eurordis.org)
- Childhood (< 15 years) Cancer Incidence in Europe: 1 in 6250


- Brain Tumours: 19%
- Neuroblastoma: 8%
- Soft Tissue Sarcoma: 7%
- Wilms Tumour: 6%
- Lymphoma: 13%
- Leukaemia: 30%
- Bone Tumours: 5%
- Retinoblastoma: 3%
- Liver Tumours: 1%
- Other (VRT): 8%

Rare Disease Definition: 1 in 2000   www.eurordis.org

Childhood ( < 15 years) Cancer Incidence in Europe: 1 in 6250

Paediatric Cancer is a public health challenge

- 6,000 children and young people die of cancer in Europe each year
- The quality and availability of paediatric cancer care widely varies across Europe
- 10% to 20% of them die from curable forms of cancer where quality care is not easily accessible.
- The outcome gap is even larger for paediatric cancers with poor outcomes
Will enhance ‘Cross-border healthcare’

- Linking pre-existing reference centres with tumour boards to provide cross border advice.
- Identification of the target groups: children with special diagnostic and therapeutic needs requiring a particular concentration of resources or expertise.
- Improving access to high-quality health care for children with cancer whose conditions require specialised resources or expertise not widely available due to low case volumes and lack of local resource.
- Provision of healthcare to children and young people with cancer in a Member State other than the Member State of affiliation.
Stakeholders

- More than 60 Partners (Health care professionals, Hospitals, Institutes) from 17 countries
  - 18 core partners from 9 EU countries
  - > 50 Collaborating professional partners

<table>
<thead>
<tr>
<th>Collaborating partners</th>
<th>Number</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Eastern European</td>
<td></td>
<td>20%</td>
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<tr>
<td>Western European</td>
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<td>80%</td>
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- Involving parents and patients
- 8 Work Packages
Paediatric Oncology in Europe
Background

- **Quality of the partnership**
  - European Society for Paediatric Oncology
  - Integration
    - European Clinical Research Council (SIOPE - CRC) for paediatric oncology (NAPHOS / ECTG)
    - Childhood Cancer International (CCI) - Integration of parents and patients groups
    - Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer: PanCare.
  - Long standing successful relationships
    - In EC funded projects
      - [www.encca.eu](http://www.encca.eu), [www.pancaresurfup.eu](http://www.pancaresurfup.eu)
    - In European Clinical Trial Group (ECTG) environments,
    - International meetings & stakeholder policy events including European Parliament
The PO-ERN Potential
CRC members: Chairs of European Paediatric Oncology Clinical Trials Research Groups

>30 years of European collaboration within paediatric cancer entities

- CWS (Cooperative Weichteilsarkom Studiengruppe or Cooperative Soft Tissue Sarcoma Study Group)
- EBMT (European Group for bone marrow and stem cell transplantation - Paediatric Working Party)
- EICNHL (European Inter-group cooperation on childhood and adolescent Non Hodgkin Lymphoma)
- SIOP-RTSG (SIOP Wilms Tumour)
- I-BFM (The International BFM Study Group)
- EHL (European Hodgkins Consortium)
- EpSSG (European Paediatric Soft Tissue Sarcoma Study Group)
- EURAMOS (osteosarcoma)
- Germ Cell Tumours
- Histiocyte Society
- SIOPEL (SIOPE-Epithelial Liver Tumour Study Group)
- SIOOPEN (SIOP Europe Neuroblastoma Group)
- ITCC (Innovative Therapies for Children with Cancer)
- EWOG-MDS (myelodysplasia)
- EURO-E.W.I.N.G.
- UK Novel Agents Subgroup
The PO-ERN Potential
CRC Members: Chairs of the National Societies of Paediatric Haemato-Oncology in Europe

2015:
31 countries
1564 members

LEGEND SIOPE
- Members of SIOPE (EU)
- Members of SIOPE (non-EU)
- Non-members of SIOPE, with NaPHOS (EU)
- Non-members of SIOPE, without NaPHOS (EU)
- Non-members of SIOPE, without NaPHOS (non-EU)
Telemedicine, IT solutions and tools are the basis for this project
ExPO-r-Net PO-ERN

Roadmap

- Addressing needs and challenges of cross-border healthcare co-operations and current expert fragmentation
  - Identifying **special therapeutic needs** of young people with cancer requiring high expertise interventions
    - **Examples:** special surgery, radiotherapy (proton therapy), stem cell transplants
  - Addressing the **challenges**:
    - **Examples:** costs, resources, psychological burden and ethical aspects
  - Identify European institution ready to engage as reference centres by establishing a/o rolling out **virtual tumour boards for cross border advice**
  - Identify European Institutions /hospitals offering top level **expertise for special therapeutic interventions and referrals**

Roadmap guidance for Health Care Providers
Increased transparency for affected Families

WP4 Lead: RUTH LADENSTEIN
Roadmap: Retinoblastoma

- **Background**
  - A rare malignancy of young children with excellent survival.
  - 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.
  - Actual status: highly specialized multidisciplinary care in a few centres (global leaders), still fragmented in EU countries with low patient accrual.
EURbG Hubs of Coordination (HoC)

Current coverage
Centres included in survey n=31
## EURbG
### Varying Hubs of Expertise

<table>
<thead>
<tr>
<th>HoC</th>
<th>#Pts</th>
<th>Intra-arterial</th>
<th>Brachytherapy</th>
<th>Research lab</th>
<th>Imaging</th>
<th>Extraocular</th>
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WP8 Lead: GIANNI BISOGNO
Roadmap:
Very Rare Tumours

Background VRT

- VRT represent a range of very different entities. Each of them own peculiar diagnostic, clinical, biological and treatment features.
- VRT - even large paediatric oncology centres see very few cases each year
- No standard treatment to recommend
- Often special diagnostic and treatment skills needed not available in every centre, i.e. special surgery according to site or radiotherapy technique
- VRT in need of expert supervision with “knowledge of the tumour “
- Need to build the evidence!

WP8 Lead: GIANNI BISOGNO
Integration of all VRT in a single framework.
- Not different networks dedicated to single VRT.

Advice on Diagnostics and Treatments for Children with VRT
- Necessary expertise cannot be located in a single centre.

Joint advice and supervision by a board of VRT experts in a VRT virtual tumour board
VRT – ERN Structure

Need for complex governance structure!

VRT European Reference Network

ERN Website

www.rarecancer-children.eu

Advisory system

International Consultation Desk (Dortmund)

Groups of Experts

Pancreatoblastoma
PPB, rare gonadal tumors,
thymic tumors, ………….

Coordinating Board

National VRT HoC

Pediatric Oncology Centre

Pediatric Oncology Centre

Pediatric Oncology Centre

Pediatric Oncology Centre

WP8 Lead: GIANNI BISOGNO
A Cross Border Health Care NEED: PO Clinical Centres in European Countries with Low Health Expenditure Rates (LHEAR)


Self assessment questionnaire to LHEAR treatment centres to check European Standards of Care implementation

- Identification of centres in Central/Eastern Europe
- Future counterparts to ERN “hubs of coordination” (HoC) via virtual tumour boards.
- Pilot phase: evaluation in 5 potential HoCs and 2 LHEAR partners
  (Sofia - Bulgaria, Bucharest - Romania)

<table>
<thead>
<tr>
<th>Total Health Expenditure (per capita) US $</th>
<th>Countries</th>
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<td>&gt; 2,000.-</td>
<td>Czech Republic, Slovakia, Slovenia</td>
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<td>1,400.- to 1,800.-</td>
<td>Croatia, Estonia, Hungary, Lithuania, Poland</td>
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<tr>
<td>1,100.- to 1,200.-</td>
<td>Bulgaria, Latvia, Serbia</td>
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<tr>
<td>&lt; 1,000.-</td>
<td>Belarus, Bosnia and Herzegovina, Republic of Macedonia, Romania, Ukraine</td>
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IT STRATEGY FOR NETWORKS

VIRTUAL TUMOUR BOARDS

- Creation of an interoperability architecture for ExPO-r-Net
- ERN virtual tumour board based on E-Health
- Move qualified information frequently ..... but patients only electively for special health care interventions!
eHealth Interoperability Architecture for ERNs

Reliable, secure, standardized and managed web/videoconferencing solution

App 1
virtual late effects centre (Survivorship Passport) (CINECA)

App 2
Case Consultation Forums (VRT, SIOPEL) CINECA

App 3
Tumour Board Web Application (AIT)

App 4
... (additional Apps)

Communication services can be used by all interoperable Apps

Interfaces to ExPO-r-Net eHealth platform services

National (European) Electronic Health Record (EHR) Systems

Electronic Hospital Site Medical Record (EMR) Systems

IHE

IHE

IHE

WP5 Leaders: ADELA CANETE & GÜNTER SCHREIER
PO-Virtual Tumour Boards

- Evaluation of currently existing tumour boards through a 30-question survey
- Legal considerations
- Standard Operating Procedures (SOP)
- Results (SWOT Analysis, Example Spain)

**Strengths**
Paediatric Tumour Boards are currently integrated in the functioning of major Paediatric Oncology Units:
- In regular meetings.
- With a designated coordinator.
- With a defined core member group (Paediatric oncologist, radiologist, surgeon and pathologist).

**Weaknesses**
Lack of:
Paediatric Tumour Boards in small Paediatric Oncology Units.
- Standard operation procedures (SOPs) concerning case selection, preparation and recommendation follow-up.
- Technical/administrative support and video-conferencing facilities.
- Difficult case consultation “culture”.
- Participation in Virtual Tumour Boards.

**Opportunities:**
- Cross-border health care Directive
- ExPO-r-Net framework
- IT developments (cloud systems)

**Threats:**
- Lack of interoperability among health ICT systems.
- Case consultation compensation system.
- Liability of advice consultation.
SURVIVORSHIP PASSPORT

- Cross-border dimension of long-term follow-up: Survivorship Passport with crucial treatment and follow-up data
**Structure**

- Demographics
- Diagnosis
- Frontline treatment
- Chemotherapy
- HSCT
- Radiation therapy
- Surgery
- Relapse/Progression
- Other relevant clinical events
- Medical suggestions
- Relapse after 1° end of therapy
- Notes

ICD-O
(©WHO or Cancer registries)

ATC

New coding (215 variables)

**Before** | 2013 | 2014 | 2015
--- | --- | --- | ---
Cardiomyopathy | January-June | July-December | January-June | July-December | January-July
SMN breast cancer | | | | |
Coronary / vascular disease | Models of care / transition | | | |
CV risk / Metabolic syndrome | Female gonadal toxicity | Male gonadal toxicity | | |
Models of care / transition | | | | |
Neurocognitive deficits, fatigue | Thyroid cancer / dysfunction | | | |
Bone | | | | |
CNS & other vasculopathy | Graft deficiency | | | |
GH deficiency | | | | |
Hearing disabilities | | | | |
Tubular / glomerular injury | | | | |
Other secondary neoplasms | | | | |
Male gonadal toxicity | | | | |
Female gonadal toxicity | | | | |
IGHG & PCSF collabor | EBM method | Finishing final documents | | |
PCSF alone | | | | |
IGHG & PCSF collabor / EBM method | | | | |
PCSF alone | | | | |
IHG & EBM method | | | | |
PCSF alone | | | | |
"Pragmatic method focused on education"

14 IGHG+PCSF (2 completed + 3 ≈ completed)
3 PCSF alone (transition + 2 miscellaneous)
Survivorship Passport

- **Goals**
  - To build a virtual paediatric oncology expert reference network for late effects after treatment for cancer in childhood and adolescence
  - To translate the Survivorship passport and relevant Guidelines into multiple European language

  “...Survivor Passport is a cloud application available across countries/hospitals by any device in the internet through a secure protocol and user profile...”

- **The possibility of a mobile app for the passport is under consideration**
  - Passport download and/or search for specific information
  - Possibility of pop-up memos according to guidelines
Integrated Communication Strategy

- Consistent identity
  - Logo
  - EU acknowledgement

- Communication tools:
  - Promotional material
    - Bookmark
    - Flyer/Folder
    - Roll-up Banner
    - Pens and Post-its
  - Project bulletin:
    - Quarterly Project eBlast
    - Features in SIOPE Newsletter

Online resources:
- www.ExPOrNet.eu (incl. dissemination pack)
- Twitter #ExPOrNet

Acknowledgement of EU support: “This publication arises …”
Broad External Dissemination

**Strategic liaison:**

- ECCO – European CanCer Organisation (Member)
- SIOP – International Society of Paediatric Oncology (Continental Branch)
- Eurordis (Member)
- Rare Cancers Europe (Member)
- European Forum for Good Clinical Practice (Member)
- Health Data in Health Research Alliance (Member)
- Childhood Cancer International – CCI
- MEPs Against Cancer
Project Expected Impact

- **The strategic relevance**
  - Incorporation of expertise across Europe to help patients getting access to the best possible information, treatment and care.

- **The innovative contribution**
  - A clear roadmap
  - Fostering eHealth solutions based on interoperability and standardisation
Because access to quality advise and care saves children’s lives

Because together, we are stronger!

**The remaining major challenge for European Member States:**

- **Cross borderer financial compensation system** for virtual cross borderer tumour board advise: invested FTEs in expert hubs!
- Moving information is cheaper than moving families!
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