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EDUCATIONAL SERIES



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ADVANCE YOUR KNOWLEDGE:

How can patients benefit from ESCPs?

ESCPs: European Standards of Clinical Practice

16.12.2024

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SPEAKERS

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CCI Europe DT&C Pillar Member, ISKIERKA Foundation, Editor in Chief of www.Onkorodzice.pl, Poland

Webinar Objectives

- To raise awareness among patient representatives of the European Standards for Clinical Practice (ESCPS) and their implementation in clinical practice.
- To understand how patients/families across Europe benefit from these ESCPS.

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ESCPs: Recap and Status Update





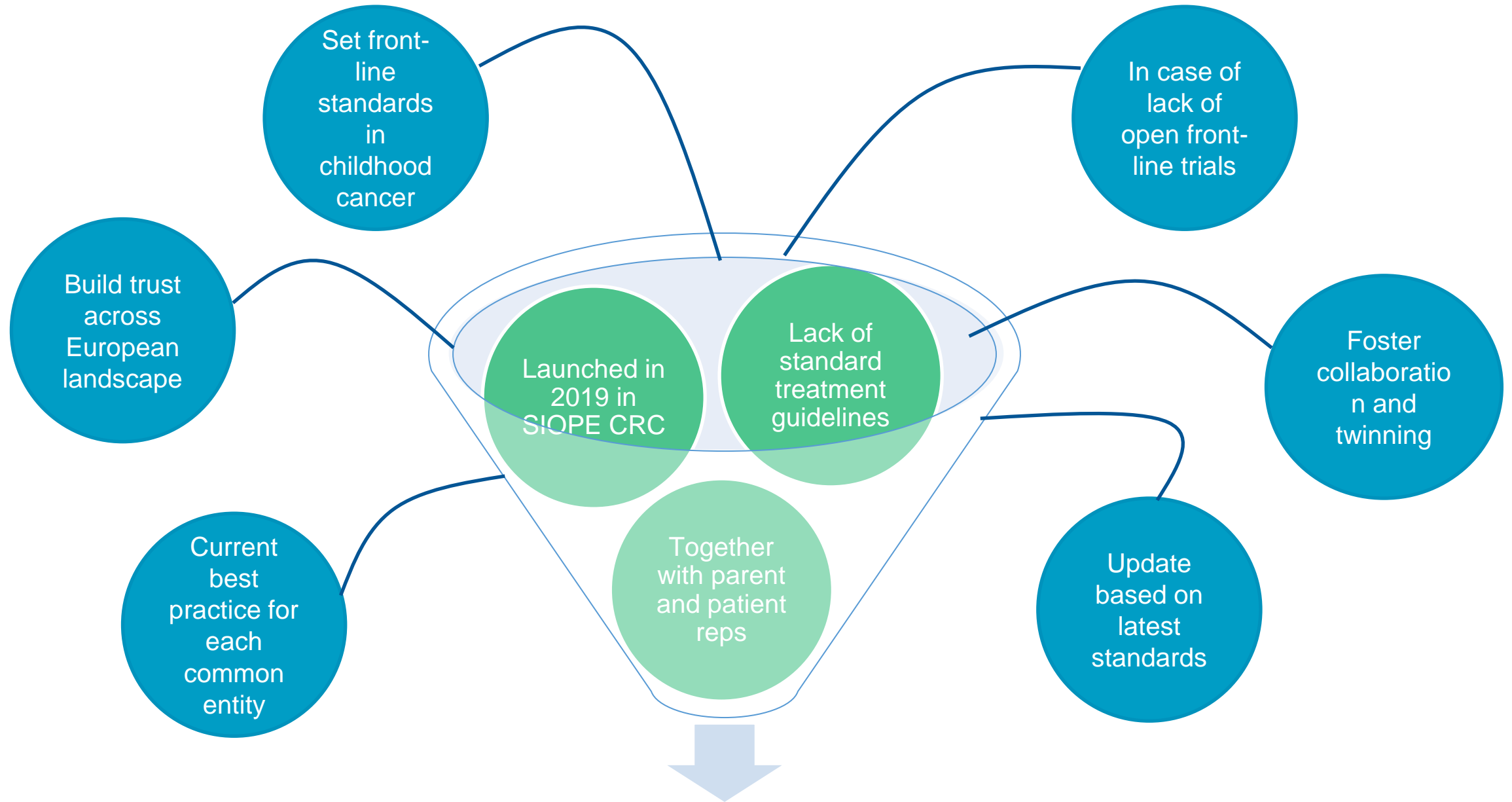
European Standard Clinical Practice (ESCP) Project

- **BACKGROUND:**

- No harmonised standard treatment recommendations for Paediatric Cancer across Europe outside of often complex randomised front-line protocols
- Launched 10/2019 with SIOPE CRC stakeholder working session together with parent and patient representatives

- **AIMS:**

- To set the front-line childhood cancer standards and built trust across European landscape by developing clinical recommendations reflecting **current best practice for each common childhood cancer type**
- For use when or where **no frontline trials are open** and to be updated when new evidence-based standards become available
- To **foster collaboration** and twinning activities to upscale skills in state-of-the-art diagnostics, medical interventions & care including psychosocial aspects



Set front-line standards in childhood cancer

In case of lack of open front-line trials

Build trust across European landscape

Launched in 2019 in SIOPE CRC

Lack of standard treatment guidelines

Foster collaboration and twinning

Current best practice for each common entity

Together with parent and patient reps

Update based on latest standards

European Standard Clinical Practice (ESCP) Project

26 ESCPs launched

10

- Acute Lymphoblastic Leukemia (ALL)
- Medulloblastoma
- Childhood Intracranial Germ Cell Tumours
- Adrenocortical Tumours
- Salivary Gland Carcinoma
- Nasopharyngeal Carcinoma
- Pleuropulmonary Blastoma
- Pediatric-Onset Langerhans Cell Histiocytosis
- Non-Hodgkin Lymphoma
- High-Risk Neuroblastoma

2017-2022

14

- Acute Myeloid Leukemia (AML)
- BTG Overview Document
- Rare CNS embryonal and sarcomatous tumours and Astroblastoma, MNI-altered
- Ependymoma
- Craniopharyngioma
- Low Grade Glioma
- Advanced intraocular unilateral retinoblastoma
- NUT carcinoma
- Ewing Sarcoma
- Low-risk NBL
- Rhabdomyosarcoma
- Familial Leukemia
- Front line and relapsed Osteosarcoma
- Renal Tumours

2022-2023

2

- High Grade Glioma
- Atypical Teratoid Rhabdoid Tumours

UNDER DEVELOPMENT

- Choroid Plexus Tumours
- Hodgkin's Lymphoma
- Myelodysplastic Syndromes
- Non-Rhabdomyosarcoma Soft Tissue Sarcoma
- Pineal blastoma
- Palliative Care
- Acute Myeloid Leukemia (to be updated)

2024-2027



Publication of ESCPs in peer-reviewed journals



Open access

- Rare CNS embryonal and sarcomatous tumours and Astroblastoma, MN1-altered
- Familial Leukemia
- Front line and relapsed Osteosarcoma
- Childhood Intracranial Germ Cell Tumours
- BTG Overview Document
- Low Grade Glioma
- NUT carcinoma

Published

- Pineal blastoma
 - Atypical Teratoid Rhabdoid Tumours (ATRT)
 - Choroid Plexus Tumours
 - Ependymoma
- SUBMITTED**
- Medulloblastoma
- ACCEPTED FOR PUBLICATION**
- High Grade Glioma
 - Craniopharyngioma

Expected in 2024

- Hodgkin's Lymphoma
- Myelodysplastic Syndromes
- Non-Rhabdomyosarcoma Soft Tissue Sarcoma
- Palliative Care
- Acute Myeloid Leukemia (AML)
- Advanced intraocular unilateral retinoblastoma
- Ewing Sarcoma
- Low-risk NBL
- Rhabdomyosarcoma
- Renal Tumours
- Acute Lymphoblastic Leukemia (ALL)
- Adrenocortical Tumours
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- Pleuropulmonary Blastoma
- Pediatric-Onset Langerhans Cell Histiocytosis
- Non-Hodgkin Lymphoma
- High-Risk Neuroblastoma

Under development



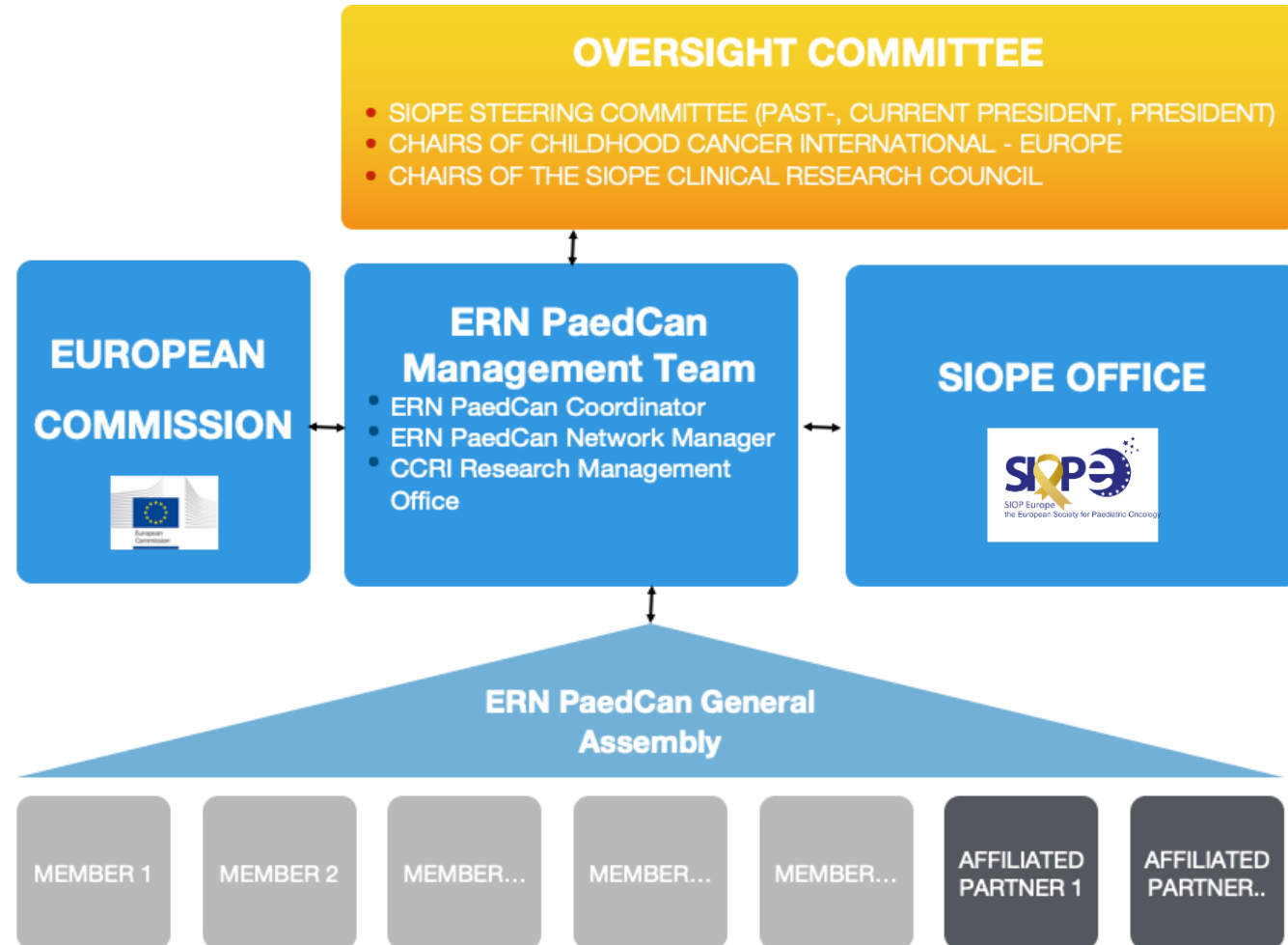
ERN PaedCan Oversight Committee:

A structure to drive the common agenda with and for the European PO Community



...provides views of parents and survivors

...volunteers for ESCP project identified!



2

ESCPs Clinical Implementation and Patient Communication

- **Two pediatric oncology centers**
- Knowledge on ESCP was disseminated to all pediatric oncologists in the country
- Physicians are in charge to inform parents on existing guidelines and discuss it with the family if needed

Organization of care for children with cancer and rare blood diseases in Lithuania



Vilnius University Hospital Santaros Klinikos
Non-malignant hematology
Solid tumours, lymphomas
Leukemia
Hematopoietic stem cell transplantation

Lithuanian University of Health Sciences Kaunas Clinics
Non-malignant hematology
Solid tumours, lymphomas

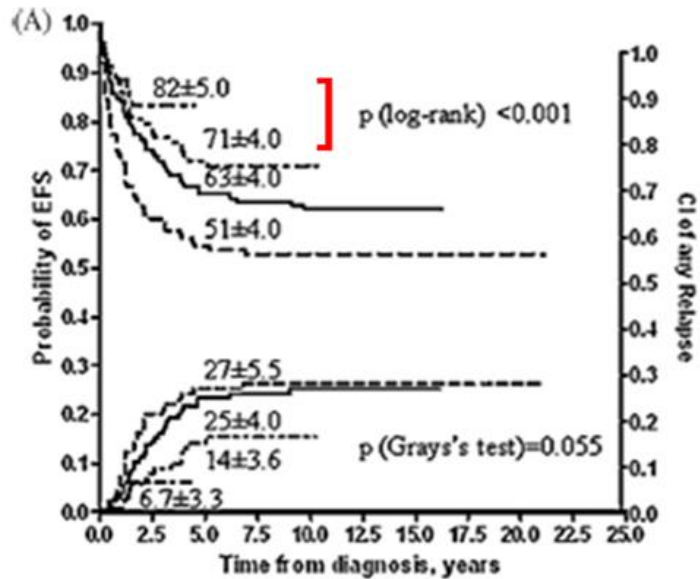
Total number of inhabitants 2.88 million (01.01.2024)
The number of children under 18 years in 2023 was 503,3

<https://osp.stat.gov.lt>

2

Collaboration with Nordic countries within the NOPHO ALL-2008 protocol 2008-2018 (n = 176)

EFS increased 11% within 5 years*



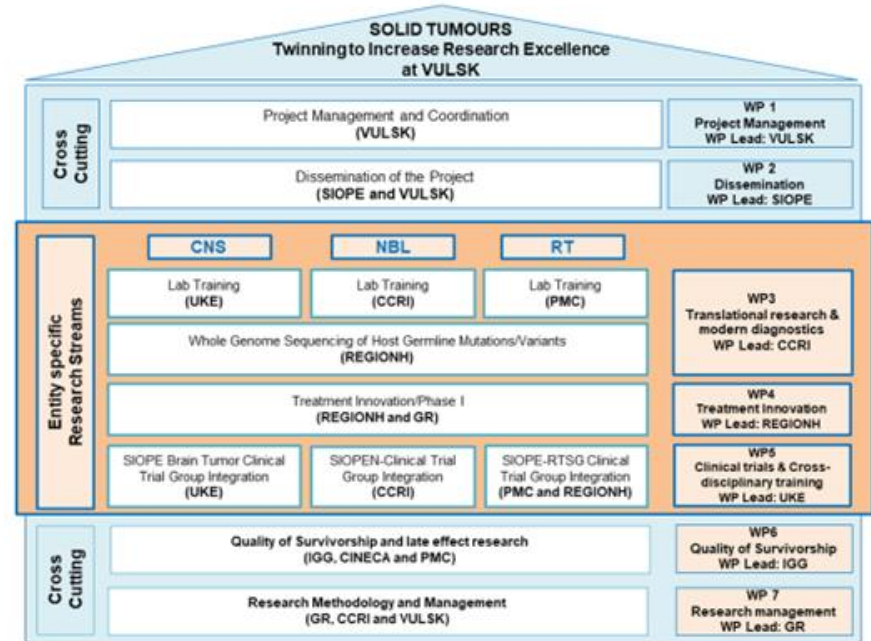
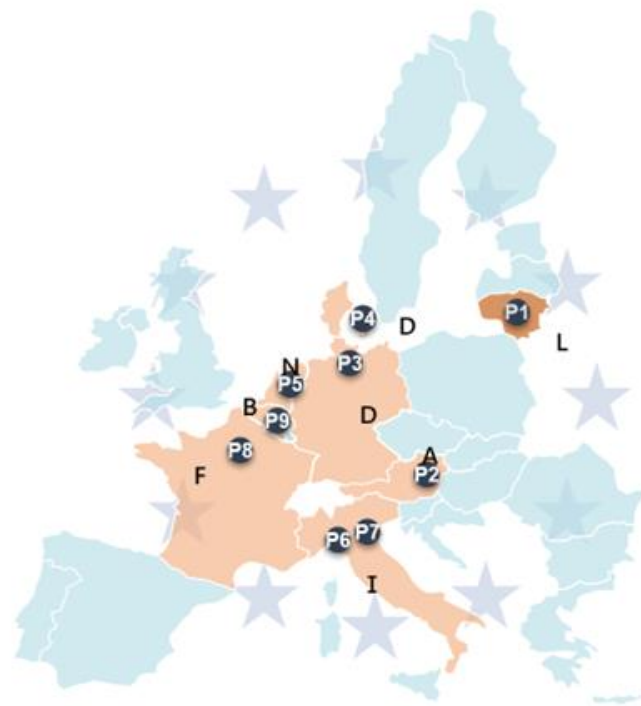
1984-2016 Nordic countries

Since 2016 Nordic and Baltic countries

*Vaitkeviciene et al. Medicina. 2014



Twinning in Research and Education to improve survival in Childhood Solid Tumours in Lithuania



- ERN-PaedCan impact
- Expansion of clinical trials
- ESCP for non-trial patients



3

Where can Patient Advocates find information about ESCPs?

- In Poland parents do not know much about the ESCP documents and are looking for information about the best methods of treatment.
- Can you please explain the involvement of Poland in ERN-PaedCan?

3

Where Patient Advocates can find information about ESCPs

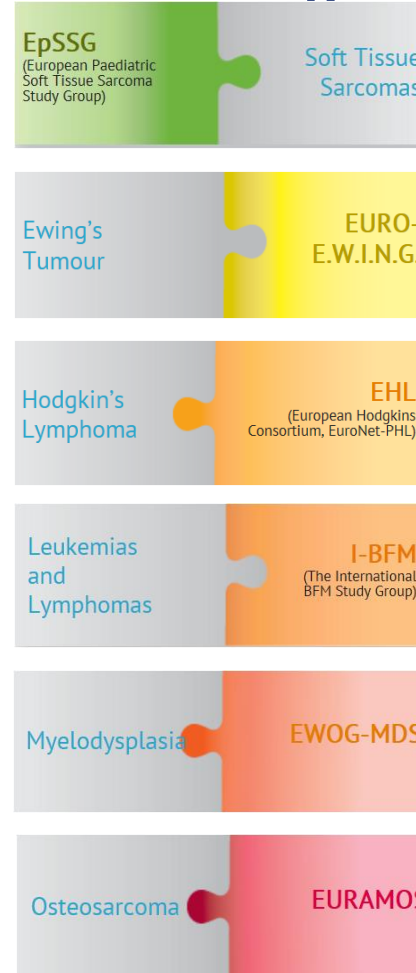
- General Information and background on the project on the ERN PaedCan website
- Some ESCPs already have accompanying webinars
- Webinars for all ESCPs will be produced until 2027
- Current links to recordings are expired (limitation of previous platform), new solution is being worked on
- Slides are available

3 ESCP document access

- ESCP files are available for SIOPE members in the SIOPE portal (password protected)
- Link to portal on ERN PaedCan website
- Under discussion right now:
 - Availability for CCI-E members in the Knowledge Hub

16 European SIOPE Clinical Trial Groups

3 Overarching Organisations



4

ESCP use in geographical Europe

- In Bosnia and Herzegovina there are three pediatric oncology centers
- Two Associations and three Parent houses
- The survival rate for pediatric cancer treatment is 80%.
- Medical institutions in BiH lack the capability to perform complex procedures such as solid tumor sarcoma surgeries and bone marrow transplants.
- Our medical professionals do not have access to ESCPs and therefore do not utilize the protocols outlined in them.



Hospitals and Association in Bosnia and Herzegovina

Cancer hospitals

- University Clinical Centre Sarajevo
- University Clinical Centre Tuzla
- University Clinical Centre Banja Luka

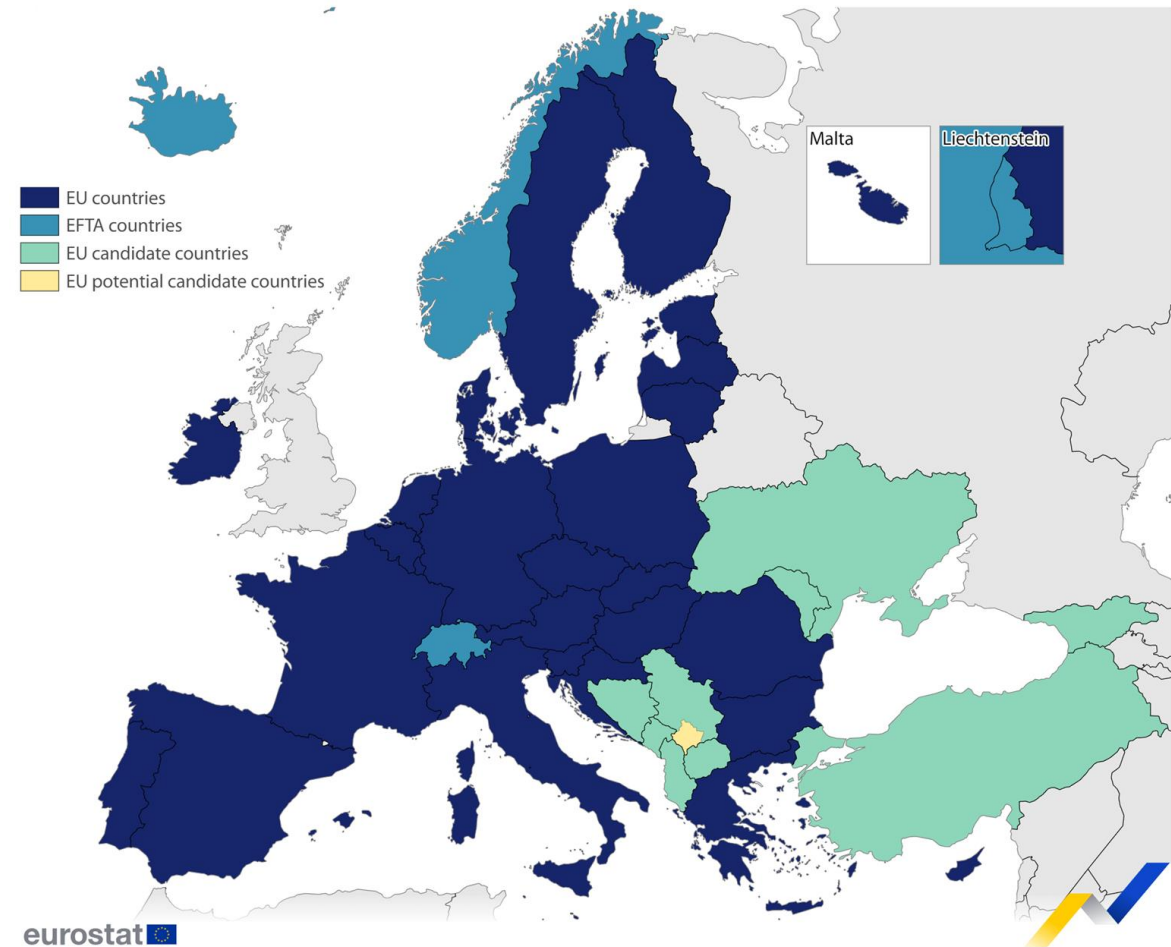
Association

- Heart for kids with cancer
- Association Iskra Banja Luka

4

ESCP use in geographical Europe

- Healthcare is a national competency
- ESCPs are written for all clinicians from geographical Europe
- Any SIOPE member clinician can access the documents
- NaPHOs together with national Patient Advocate Organisations need to lobby with local politics for ESCP implementation



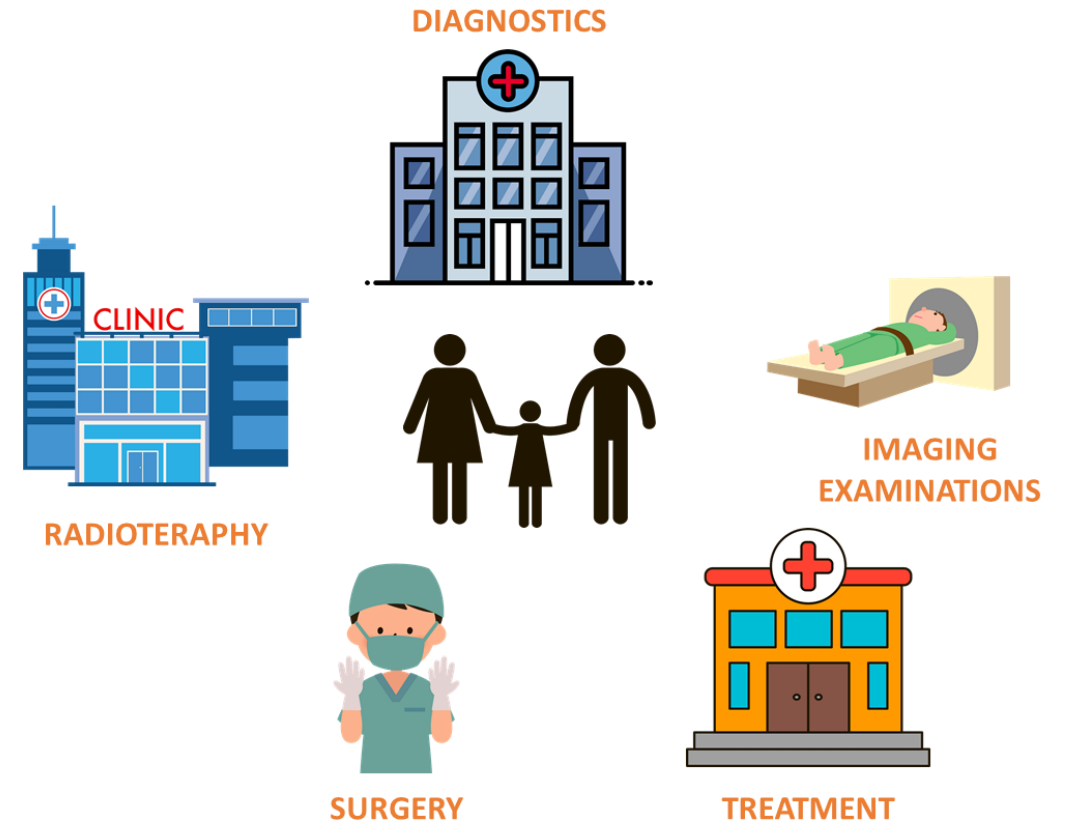
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The role of ESCPs in different healthcare settings?

Example:

Bulgaria is one of the countries where there is no multidisciplinary approach in treatment of childhood cancer, especially for rare types of cancers, like solid tumours, like sarcoma.

In most cases, the different parts of the treatment process are made in different separate clinics.



5

The role of ESCPs in different healthcare settings

Example of Sofia, Bulgaria

Pediatric Oncohematology Department, University Hospital "Tsaritsa Johanna-ISUL"

- ERN PaedCan Affiliated Partner
- Since February 2024 new Head of Clinic: Dr. Boriana Avramova,
- Chair of national paediatric haematology group as of Sept 2024
- Seize opportunity to raise awareness on ESCP project, international case consultation via CPMS 2.0
- Strengthen collaboration in ERN PaedCan



What forms of collaboration could there be between patient representatives and clinicians regarding ESCPs?

- Per country designated patient representatives that are closely collaborating at national level with clinicians who are involved in ERN-PAEDCAN can get direct access to ESCP documents (information level)
- Patient Organizations should raise awareness about ESCPs in countries where there is not yet an intensive exchange with ERN PaedCan.
- Workshops and trainings for both HCPs & Pat Reps. to jointly develop of possible applications on the national level?
 - Everyone is welcome to attend ESCP webinars
 - Current links to recordings are expired (limitation of previous platform), new solution is being worked on
 - Topic should be integral part of the national paediatric haemato-oncology meetings

Further questions?

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NEXT WEBINAR IS:

Around the ERN-PaedCan Virtual Tumor Board 2.0 in 80 Minutes

ON 23.03.2024 @ 17:00 CET



www.ccieurope.eu



CPMS 2.0

- Available for free
- Follows EU data protection regulations
- Can be used for national and international case discussions

ON 23.03.2024 @ 17:00 CET



Thank you for your time



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