



For a Brighter Future for Children & Adolescents with Cancer



*Create a brighter future for children
and adolescents with cancer*

**International Childhood Cancer
Awareness Day (ICCD 2019)**

6 March 2019
15h00 – 17h00

European Parliament
Brussels, Belgium



Furthering the potential of the European Reference Network model across the care continuum

Prof. Ruth Ladenstein
SIOPE Board member, ERN PaedCan Coordinator
Children's Cancer Research Institute, Vienna - Austria

6 March 2019
European Parliament, Brussels, Belgium

The Childhood Cancer Journey



European
Reference
Network

for rare or low prevalence
complex diseases

 **Network**
Paediatric Cancer
(ERN PaedCan)

- A life-long endeavour with many profound challenges
- Dedication of many needed to achieve long-term cure and sustained quality of life!
- As of today substantial inequalities in childhood cancer cure rates exist across Europe

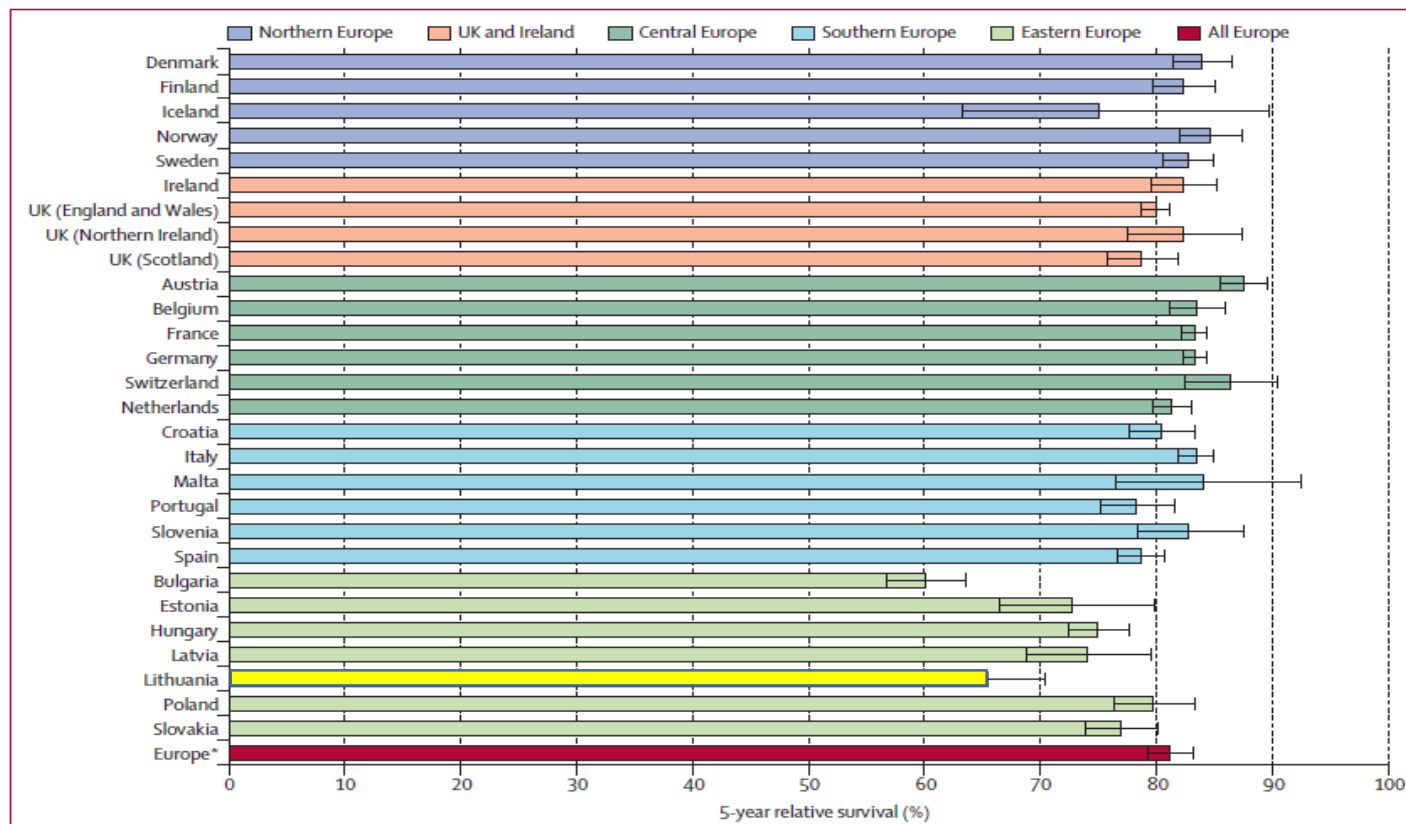


This project is funded by the
European Union's Health
Programme (2014-2020).





Five year overall survival of children treated for solid tumors (non-CNS) in 2000-2007



Gatta et al. Lancet Oncol. 2014

ERN PaedCan: Vision



European
Reference
Network

for rare or low prevalence
complex diseases

Network
Paediatric Cancer
(ERN PaedCan)

- Equal and possible best paediatric cancer care and outcomes no matter where in Europe children live
- EC Vision on ERNs: A sustainable European Structure!



This project is funded by the
European Union's Health
Programme (2014-2020).



The Childhood Cancer Journey

Major Challenges



European
Reference
Network

for rare or low prevalence
complex diseases

 Network
Paediatric Cancer
(ERN PaedCan)

- **Accurate and rapid diagnosis using modern diagnostics**
 - Capitalising from the ERN PaedCan networks to access best diagnostic procedures
 - **Correct risk estimate** based on elaborated pathohistology & modern biological techniques & adequate staging of disease extent
- **Right therapeutic choice**
 - Wrong decisions have major impact on survival chances and quality of potential cure
 - **Every child with cancer needs to be discussed with experts in multidisciplinary childhood cancer tumour boards – locally or internationally !**
- **Appropriate long-term life-long follow –up**
 - **Transition** of former childhood cancer patients into adult survivors :
Need of adequate long-term care models
 - Implementation of the **survivorship passport** concept (a treatment and risk summary for individual patients) capitalising of upcoming e-Health structures
 - **Registration of follow-up events** crucial to fully understand treatment burden



This project is funded by the
European Union's Health
Programme (2014-2020).



Capitalising on ERN PaedCan structures: Fostering Cross-border Health Care



European
Reference
Network

for rare or low prevalence
complex diseases

Network
Paediatric Cancer
(ERN PaedCan)

- **Access to Virtual Expert Tumour Boards**
 - Medical expertise and knowledge travels rather than patients
 - ☞ Recognition as a major health-care tool needed with adequate refund of expertise provided
- **ERN PaedCan Roadmap –a tool for care pathways!**
 - Defines current treatment standards
 - Identifies expert sites of European Clinical Trial Groups
- **Proportionate & appropriate Cross-Border Healthcare**
 - Unites the best specialists across Europe to tackle **complex or rare paediatric cancer conditions** that require **highly specialized interventions** and a **concentration of knowledge and resources**.
 - ☞ Identifies patients needs early and supports the right therapeutic pathway choices
 - ☞ **Challenge: Access to innovation !**
CBHC arrangements currently (S2) do not cover treatments in early development and hence prohibit access of patients to innovation



This project is funded by the
European Union's Health
Programme (2014-2020).



Innovation in Patient Pathways is Key!



European Reference Network
for rare or low prevalence complex diseases

Network
Paediatric Cancer
(ERN PaedCan)

■ EU Clinical Patient Management System (CPMS)

- Information travels rather than the patients – concept is brilliant!
- The system for free – excellent !
- Modern and GDPR compliant consulting system

■ But

- Work intensive processes and major time investments of experts
- No reimbursement scheme Europe for advisory functions within health care pathways yet!

☞ **Need for a smart compensation scheme between individual HCPs across borders for virtual advise**

☞ **CPMS needs to be secured as a sustainable European structure!**



This project is funded by the European Union's Health Programme (2014-2020).





**European
Reference
Network**

for rare or low prevalence
complex diseases

Network
Paediatric Cancer
(ERN PaedCan)

ERN PaedCan Members

2017

- **57 Full Members**
- **18 Members States**
- **28% members with gross national income <90% of EU average**
- **2019** new members needed to achieve European coverage of MS !



This project is funded by the
European Union's Health
Programme (2014-2020).

9



The Equality Challenge: Widening countries

- **DEFINITION:** The composite indicator of Research Excellence with a corrective threshold of 70% of the EU average was selected to distinguish those countries identified as "low Research & Innovation performing" or "Widening" countries.

These are:

- **Member States of the EU:** Bulgaria, Croatia, Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Luxembourg, Malta, Poland, Portugal, Romania, Slovakia and Slovenia.
- **Associated Countries** (subject to valid association agreements of third countries with Horizon 2020): Albania, Armenia, Bosnia and Herzegovina, Faroe Islands, Former Yugoslav Republic of Macedonia, Georgia, Moldova, Montenegro, Serbia, Tunisia, Turkey and Ukraine.

Source: http://ec.europa.eu/research/participants/data/ref/h2020/wp/2018-2020/main/h2020-wp1820-sewp_en.pdf



The Equality Challenge: LHEAR countries



European
Reference
Network

for rare or low prevalence
complex diseases

 Network
Paediatric Cancer
(ERN PaedCan)

■ Countries with low health expenditure rates (LHEAR)

(as identified in the ExPO-r-Net project (WP6 Prof. Kowalczyk))

- **>2000 U\$:**
Czech Rep., Slovakia, Slovenia
- **Between 1400 – 1800 U\$:**
Croatia, Estonia, Hungary, Lithuania, Poland
- **Between 1100-1200 U\$:**
Bulgaria, Latvia, Serbia
- **< 1000 U\$:**
Belarus, Bosna-Herzegovina, Macedonia, Romania, Ukraine

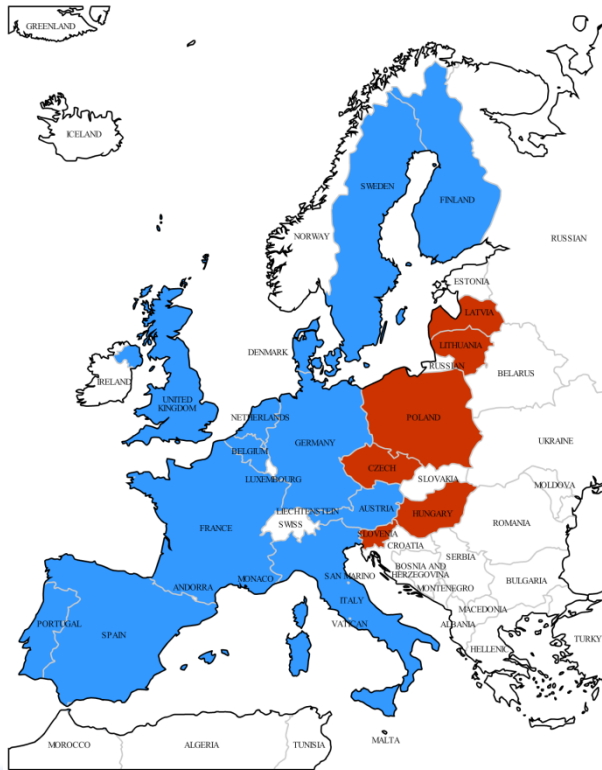


This project is funded by the
European Union's Health
Programme (2014-2020).



LHEAR countries

■ ERN PaedCan members



NON- members



Widening and LHEAR countries in ERN PaedCan



European Reference Network
for rare or low prevalence complex diseases

Network
Paediatric Cancer (ERN PaedCan)

ERN PaedCan members			
Country	Nr. of inst.	Is it a widening country?	Is it a LHEAR country?
Austria	1	NO	NO
Belgium	3	NO	NO
Czech Republ	2	YES	YES
Denmark	1	NO	NO
Finland	3	NO	NO
France	7	NO	NO
Germany	10	NO	NO
Hungary	1	YES	YES
Italy	9	NO	NO
Latvia	1	YES	YES
Lithuania	1	YES	YES
Netherlands	2	NO	NO
Poland	4	YES	YES
Portugal	2	YES	NO
Slovenia	1	YES	YES
Spain	4	NO	NO
Sweden	2	NO	NO
UK	3	NO	NO
Total:	57	7	6

Widening countries (EU members)		
	EU MS	Repr.in ERN PaedCan?
1	Bulgaria	NO
2	Croatia	NO
3	Cyprus	NO
4	Czech Republic	YES
5	Estonia	NO
6	Hungary	YES
7	Latvia	YES
8	Lithuania	YES
9	Luxembourg	NO
10	Malta	NO
11	Poland	YES
12	Portugal	YES
13	Romania	NO
14	Slovakia	NO
15	Slovenia	YES

LHEAR countries			
	Country	EU MS?	Repr.in ERN PaedCan?
1	Belarus	NO	NO
2	Bosnia-Herzegovina	NO	NO
3	Bulgaria	YES	NO
4	Croatia	YES	NO
5	Czech Republic	YES	YES
6	Estonia	YES	NO
7	FYR Macedonia	NO	NO
8	Hungary	YES	YES
9	Latvia	YES	YES
10	Lithuania	YES	YES
11	Poland	YES	YES
12	Romania	YES	NO
13	Serbia	NO	NO
14	Slovakia	YES	NO
15	Slovenia	YES	YES
16	Ukraine	NO	NO

- Challenge for equality – still a way to go!
- Needs solidarity and buy in of all MS



This project is funded by the European Union's Health Programme (2014-2020).





European
Reference
Networks

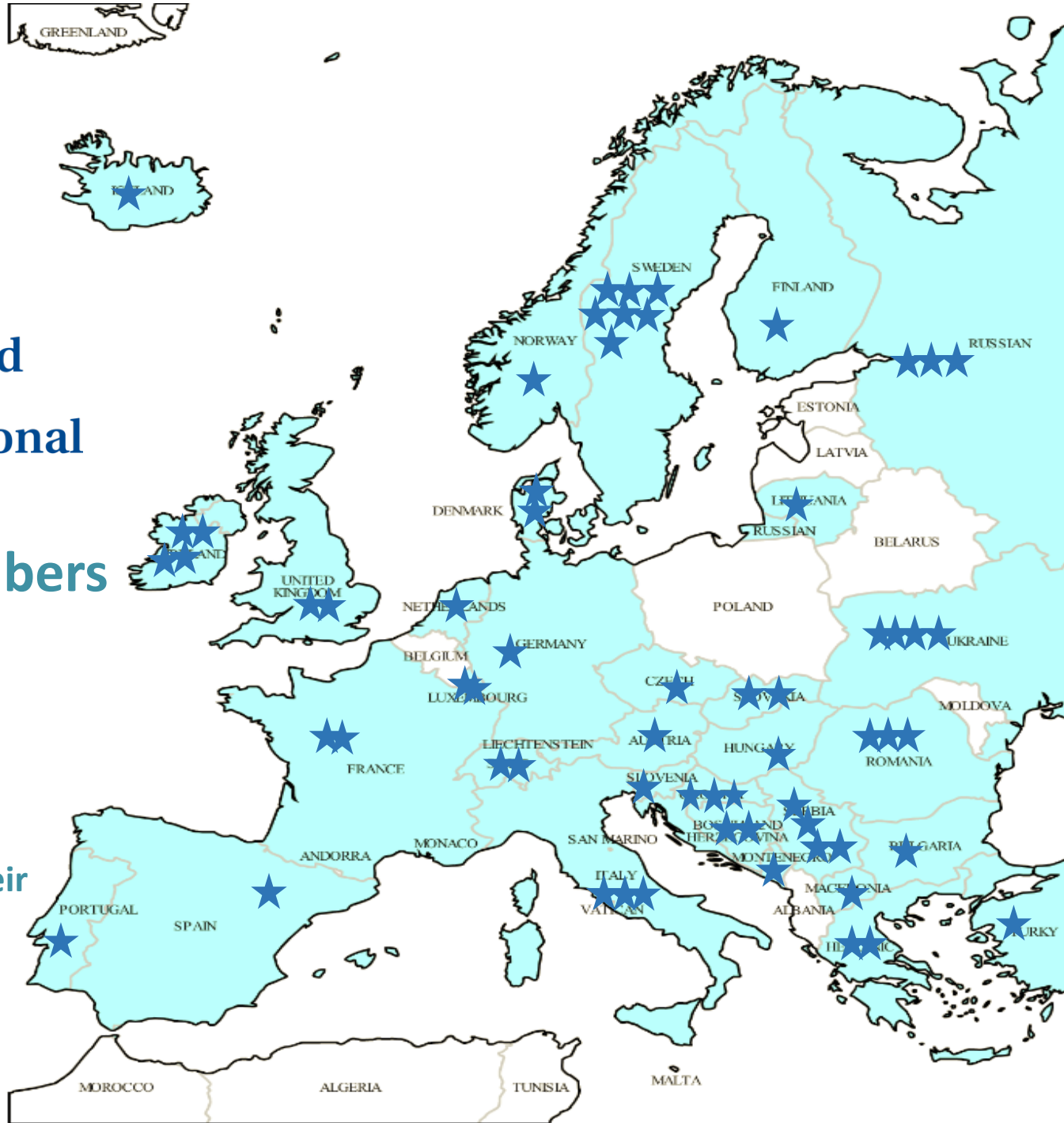


Childhood
Cancer
International

CCI Europe Members

As identified in 2017:

- 66 Parent & Survivor Organizations
- 33 Countries
- We need to listen - their needs are our strong motivation and voice !



This project is funded by the
European Union's Health
Programme (2014-2020).

“Twinning Support”



European
Reference
Network

for rare or low prevalence
complex diseases

 Network
Paediatric Cancer
(ERN PaedCan)

- Twinning of HCP across Europe for enhanced education, research and better quality in care & treatments
- Aspects of Twinning
 - Support exchange of Health Care Personnel
 - Day to day Knowledge exchange using “Twinning” within the CPMS platform
 - Continued medical education WEBinars /CME points
- ☞ To overcome inequalities across Europe “Twinning” is key and requires non-competitive funding !



This project is funded by the
European Union’s Health
Programme (2014-2020).





European
Reference
Network

for rare or low prevalence
complex diseases

 Network
Paediatric Cancer
(ERN PaedCan)

Towards a brighter future for our children with cancer

THANK YOU!



This project is funded by the
European Union's Health
Programme (2014-2020).

