

## **Special Committee on Beating Cancer (BECA) PUBLIC HEARING**

**“Cooperation is Strength: Sharing Knowledge and Data, Improving Cross-Border Care to Beat Cancer”**

***Panel 1: European Reference Networks - promoting shared expertise***

**Thursday, 15 April 2021 (13.45 – 15.45 & 16.15 – 18.15 CEST)  
(remote participation)**

**Prof. Carmelo Rizzari**

President Elect  
SIOP Europe

Even if cancer in children is a rare disease , it remains the **first cause of death by disease in Europe in children older than 1 yr**

**In Europe:**

more than **35,000** new cases are diagnosed every year

over than **6,000** young patients die every year

There are nearly **500,000** childhood cancer survivors  
**the majority** experience adverse long-term effects

There are substantial **inequalities in access** to the best available care and expertise

**20%** differences in survival rates between EU Member States

# What is SIOPE Europe?

Society with over **2000** members from **> 30** countries across Europe with ...

... a highly Collaborative Community



**19** Clinical Trial Groups

... A pan-European Representation

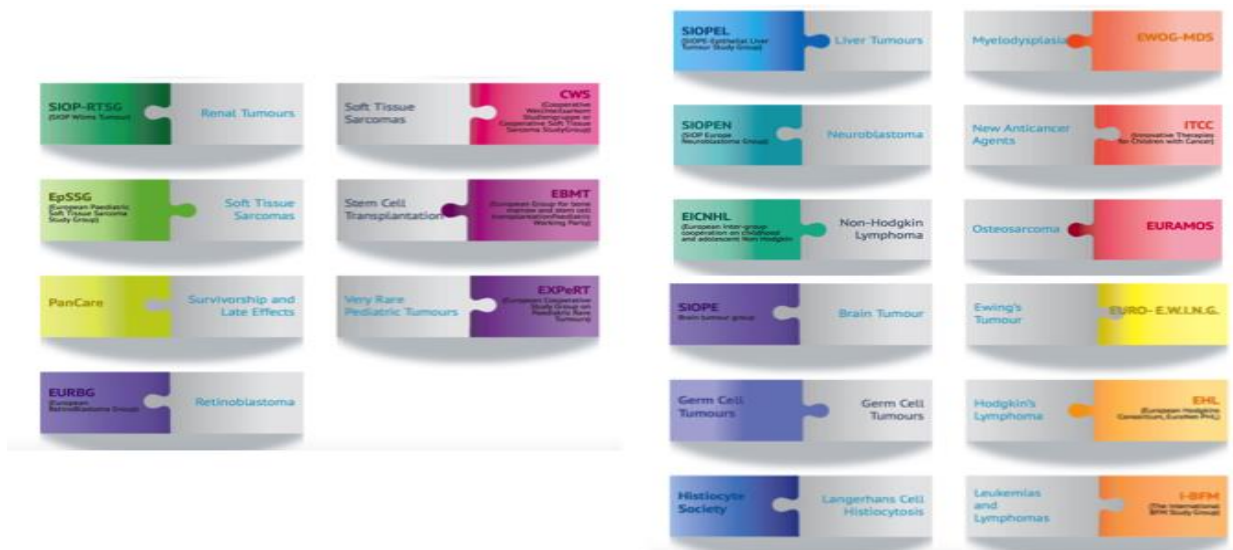


**> 30** National Paediatric Haematology-Oncology Societies

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Haem  
**I-BFM-SG**

# The example of International-BFM-Study Group in the field of pediatric acute lymphoblastic leukemia (ALL)

- ❑ ALL is the most common cancer in pediatric population, accounting for 40 cases/million of children and adolescents per year in Europe (**≈5-6,000 cases**)
- ❑ The survival outcomes have improved dramatically over the past decades, even in widening countries (still lagging behind, anyway).
- ❑ Improvements largely due to advances in the research promoted at several national but also international levels focused to a better understanding of the disease, its underlying biology and pathogenesis, to a response-based stratification (MRD) and to a risk-adapted therapy
- ❑ **NETWORKING IS ESSENTIAL – IBFMSG IS A LONG-LASTING EXAMPLE**

# The objectives of the I-BFM-SG

- **Information exchange** including preliminary results, to promote research projects in childhood leukemias and related disorders.
- To establish, **share and adapt consensus guidelines in diagnostics.**
- To activate **cooperative projects** for research.
- To study **rare problems and rare forms of leukemia.**
- To promote the use of **novel treatment strategies.**
- To apply and to perform prospective **randomized clinical trials**, using **consensus** approaches and allowing the participation of other groups.
- To increase knowledge on disease and treatment related **early and late toxicities.**
- To improve **protected dissemination** of clinically relevant information to all relevant stakeholders including the patient himself/herself.

# The countries members of the I-BFM-SG



# The international trials conducted by the I-BFM-SG in ALL

<b>Trial</b>	<b>Period</b>	<b>Population(N)</b>	<b>N. Groups</b>
IDH	1991-95	SR-ALL (355)	3 (EU)
PULSES	1995-2000	MR-ALL (2618)	8 (>EU)
ALLO-BMT	1995-2000	VHR-ALL (357)	7 (>EU)
AIEOP-BFM 2000	2000-2006	ALL (4827)	3 (EU)
Interfant-99	1999-2006	ALL<1y (482)	17 (>EU)
ALLIC-2002	2002-2008	ALL	15 (>EU)
ALLIC-2009	2009-2016	ALL	15 (>EU)
Interfant-06*	2007-2015	ALL<1y	19 (>EU)
HSCT*	2003-2010	VHR	>2 (EU)
EsPhALL*	2004-2012	Ph+ ALL	11 (>EU)
AIEOP-BFM 2009	2009-2016	ALL	6 (>EU)
AIEOP-BFM 2017	2016	ALL	6 (>EU)

**Complete overview of completed and ongoing clinical trials in:**

<https://bfminternational.wordpress.com/clinical-trials/>



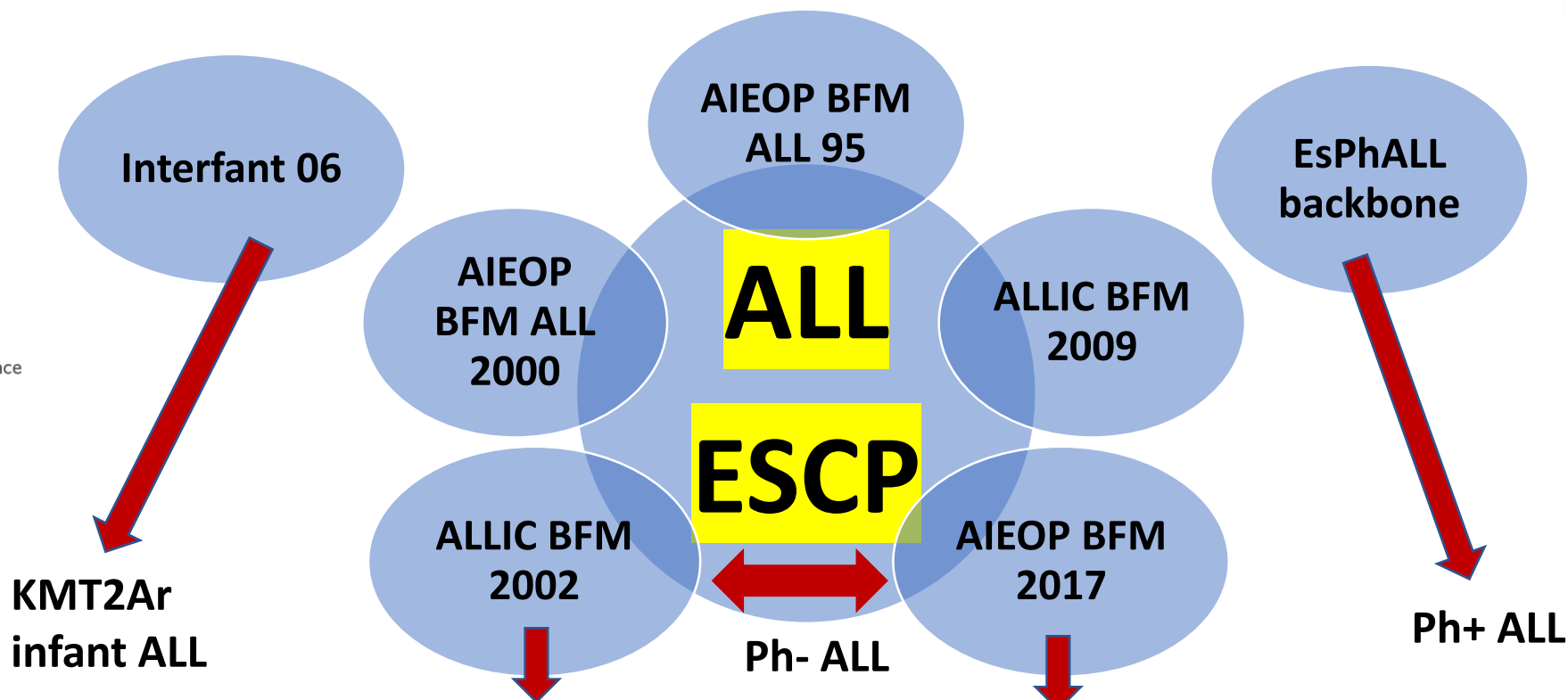


1999-2009

THE CHILDHOOD ALL "PONTE DI LEGNO WORKING GROUP"

Pontedilegno - Italy 5 May 2009

# The synergies between I-BFM-SG, SIOPE and the ERN Paed Can network in the field of ALL



- Long lasting Familiarity of European countries with a BFM approach even when more recent or ongoing trials are considered
- Proven Feasibility in developing countries
- Need to improve and standardize some aspects of diagnostics

- Implementation of new elements for risk stratification
  - ✓ Genetics
  - ✓ MRD
- Consolidated experience with ESPHALL and Interfant strategies

# BFM ALL-International Consortium 2009

## (ALLIC) EudraCT 2010-019722-13

Sponsoring Institute: University of Debrecen, Hu.

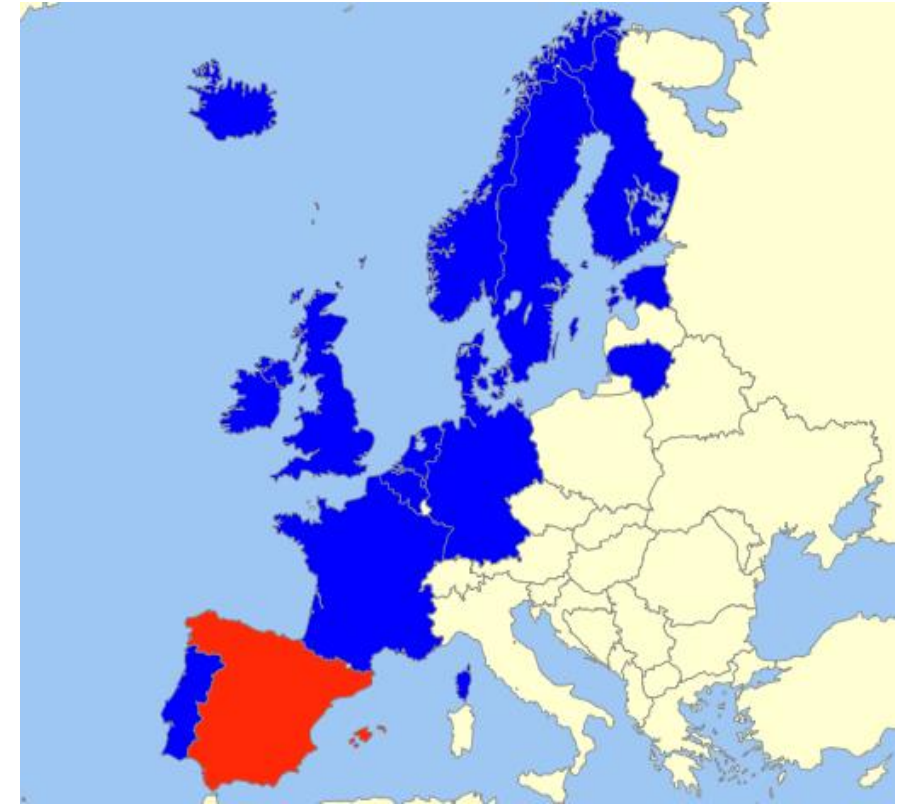


- **Members: 12/11**
- **Observers: 5**
- **Follow the study: 3**



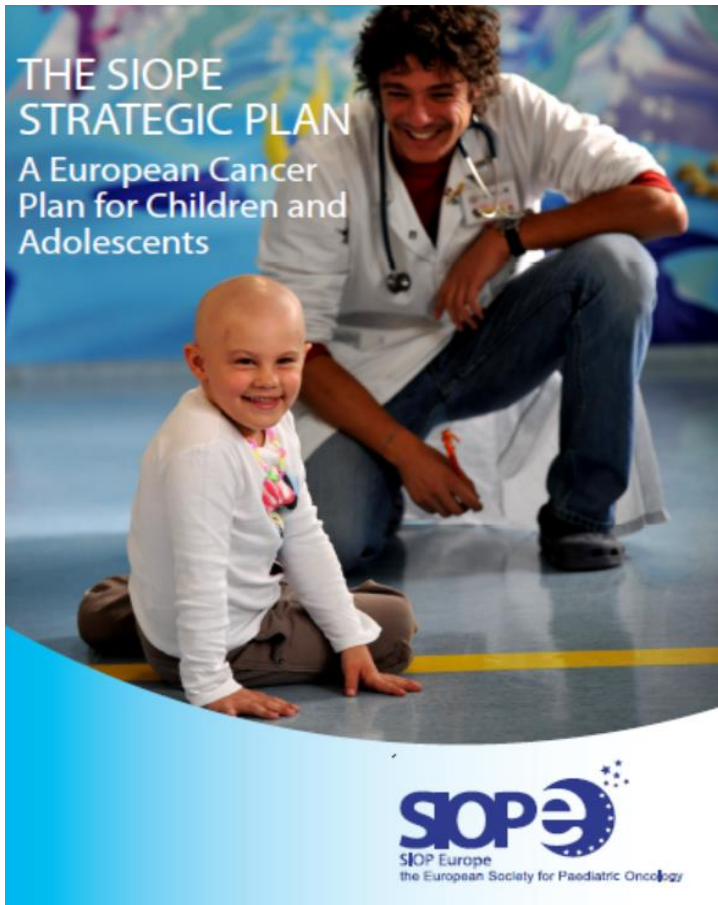
# Expansion of the patient population - ALLTogether

Study-Group	Age	Pts/year	Country
DCOG	1-18	106	NL
UKALL	1-24	419	UK
COALL	1-18	90	D
NOPHO	1-45	235	S, DK, N, FIN, IS, EE, LT
BSPHO	1-18	80	B
SHOP	1-18	55	PT
PHOAI	1-24	42	EI
SFCE	1-18	400	F
<b>SEHOP</b>	<b>1-18</b>	<b>300</b>	<b>E – candidate status</b>
Total	1-45	1427 <b>+300</b>	Western Europe



- Core countries (without Spain): Population base (CIA) 276,225,003 - if 10% of Germany: 203,690,388
- Population-based in all countries except Germany
- Improved statistical power when improved results demand larger and larger patient populations

# Sharing expertise is **a hard task**. How to expand and improve this process in all member states?



Supporting the european research networks via international sponsored programs

Simplifying the rules and rewarding the programs aimed to data sharing of clinical trials

Investing in twinning programs

Implementing rules for an equal access to innovation

Encouraging and financing the programs aimed to share expertise and standardize treatment plans.

Establishing shared rules to improve the transition of children with cancer to adulthood



***"Together we can make the difference!"***

