

**9th SPAEN Annual Conference for Organizations
Representing Patients with Sarcomas, GIST or Desmoid-Tumours
1 – 3 February, 2019
Radisson Blu Park Hotel, Athens/Greece**



**Sarcoma
Patients
EuroNet**

Welcome to Athens

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Athens Medical School*

1 February 2019

***Why is this conference
so important ?***



Collaboration

“In union there is strength”

Aesop

(Greek fabulist and storyteller)

620-564 BCS

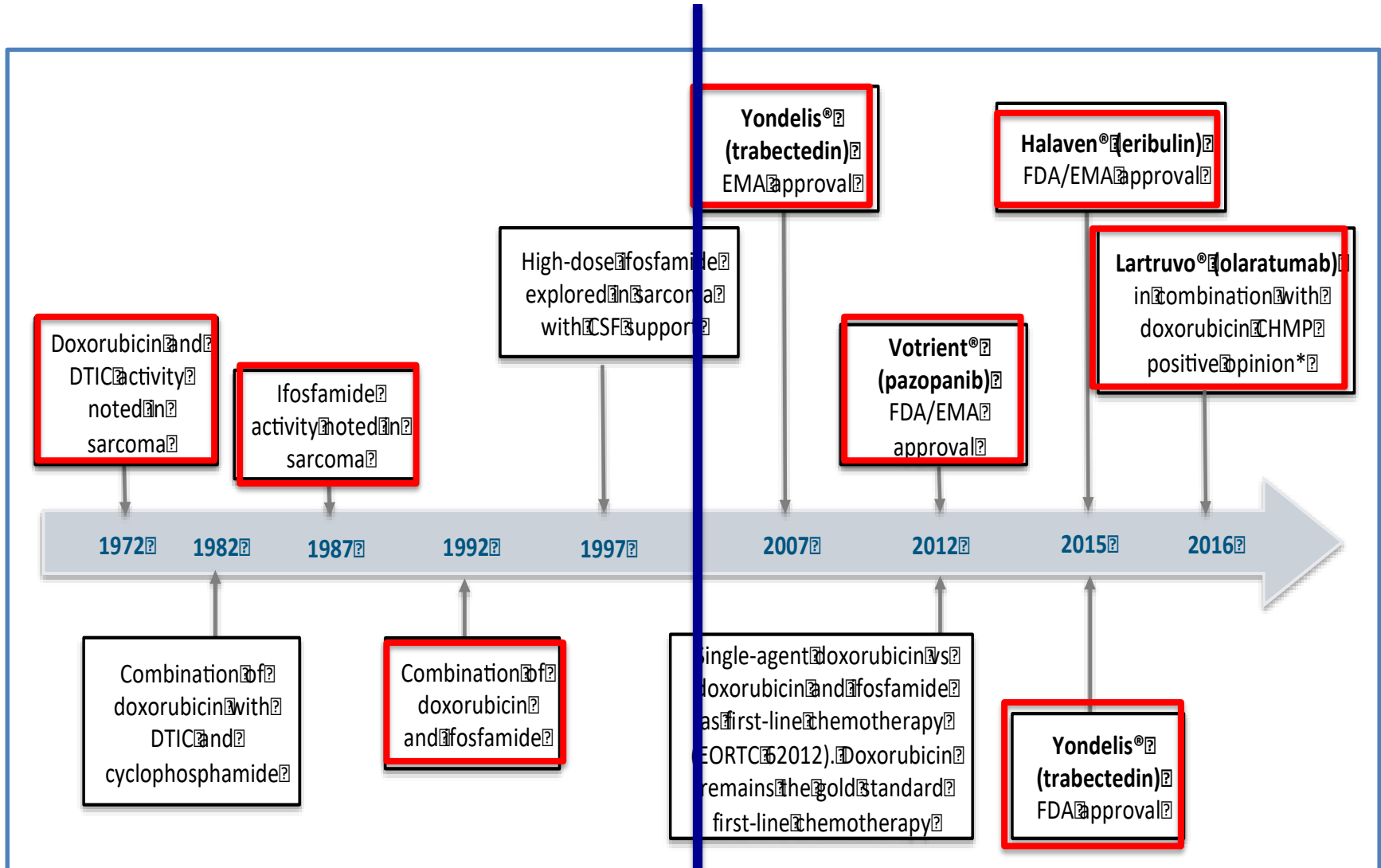


*“If you want to understand today, you have
to search yesterday”*

Pearl Buck 1892- 1973



History of Systemic Treatment in STSs



The last 2 decades the therapeutic landscape is changing rapidly..





Collaboration between institutes



Available at www.sciencedirect.com

SciVerse ScienceDirect

journal homepage: www.ejconline.com



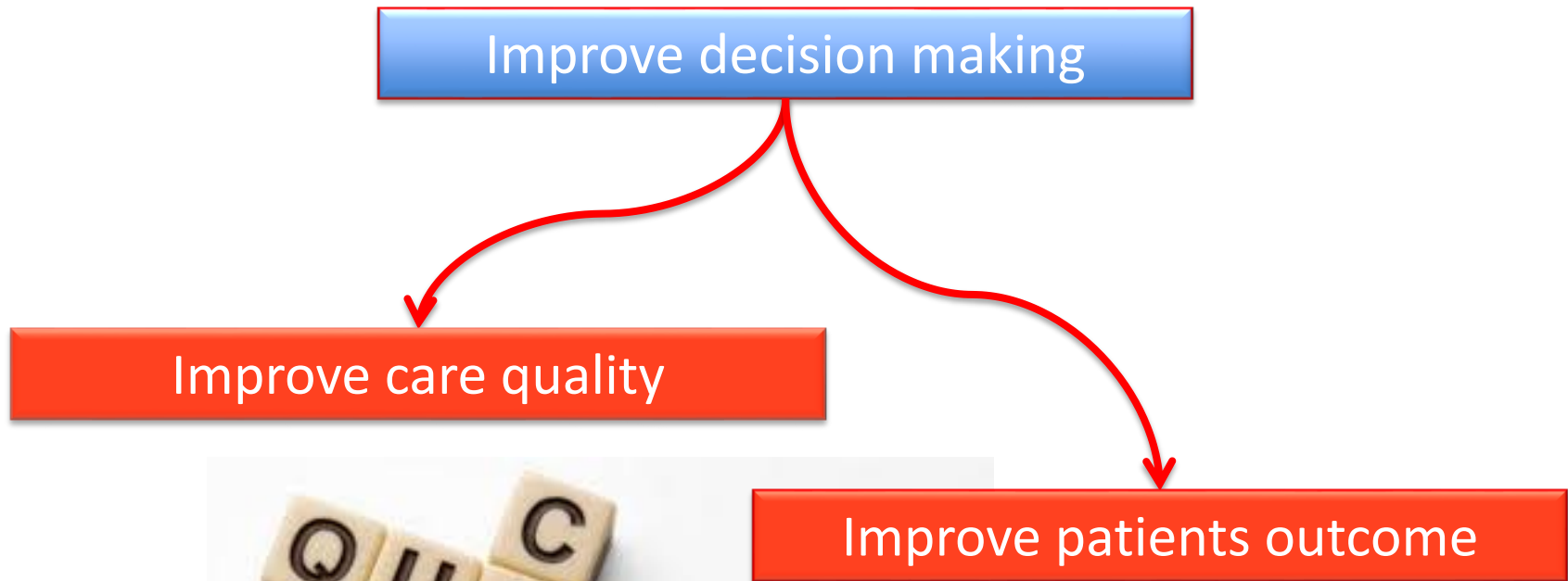
Rare cancers are not so rare: The rare cancer burden in Europe

Gemma Gatta ^{a,*}, Jan Maarten van der Zwan ^b, Paolo G. Casali ^c, Sabine Siesling ^b,
Angelo Paolo Dei Tos ^d, Ian Kunkler ^e, Renée Otter ^b, Lisa Licitra ^f, Sandra Mallone ^g,
Andrea Tavilla ^g, Annalisa Trama ^a, Riccardo Capocaccia ^g, The RARECARE working group

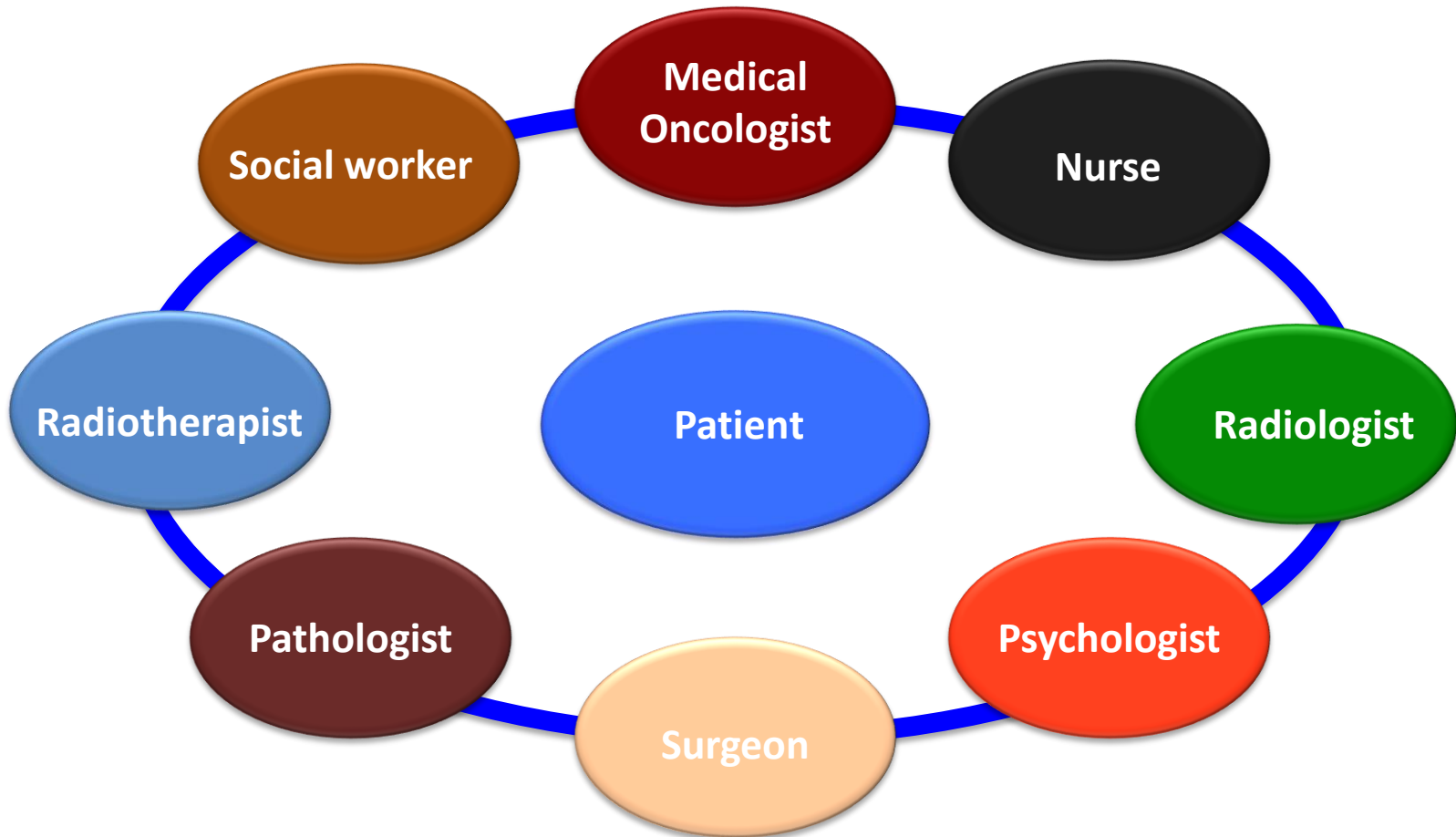
Eur J Cancer 2011;47:2493



Collaboration between different specialties: multidisciplinary approach



Who do participate in a multidisciplinary team?



Knowledge

“Knowledge is power”

Francis Bacon

(English Philosopher)

1561-1626

Knowledge



Understanding:

- *Your cancer*
- *The goals of the treatment*
- *What is chemo*



Centres of excellence

The Sarcoma Policy Checklist

February 2017



Designated and
accredited national
centres for reference
on sarcoma



Paolo Casali, Istituto Nazionale Tumori, Italy
Nora Drove, Eli Lilly & company
Sarah Dumont, Institut Gustave Roussy, France
Mikael Eriksson, University of Lund, Sweden
Alessandro Gronchi, Istituto Nazionale dei Tumori, Italy
and EORTC Soft Tissue and Bone Sarcoma
Bernd Kasper, University of Heidelberg, Germany

Estelle Lecoite, Info Sarcomes, France and SPAEN
Claudia Valverde, University Hospital Vall' Hebron, Spain
Markus Wartenberg, SPAEN & das Lebenshaus e.V., das
Wissenhaus GmbH, Germany
Roger Wilson, SPAEN
Shannon Boldon, The Health Policy Partnership
Suzanne Wait, The Health Policy Partnership

2019 SPAEN conference in Athens, Greece





European
Reference
Networks

**“will provide
highly specialised healthcare
for rare or low prevalence
complex diseases or conditions”**

EURACAN



COUNTRIES/Towns

BELGIUM (Antwerp, Brussels, Leuven, Liège)

CZECH REPUBLIC (Brno, Prague)

DENMARK (Aarhus)

GERMANY (Berlin, Essen, Mannheim, Hamburg-Eppendorf, Marburg, Würzburg)

FINLAND (Turku)

FRANCE (Lyon, Paris, Villejuif)

HUNGARY (Budapest)

ITALY (Aviano, Bologna, Candiolo, Firenze, Genoa, Meldola, Milan, Naples, Rome, Siena, Torino, Treviso)

LITHUANIA (Kaunas)

NETHERLANDS (Amsterdam, Leiden, Maastricht, Nijmegen, Rotterdam, Gronigen)

NORWAY (Oslo)

POLAND (Warsaw)

PORTUGAL (Coimbra, Lisboa, Porto)

SPAIN (Sevilla, Barcelona)

SWEDEN (Karolinska, Uppsala)

SLOVENIA (Ljubljana)

UNITED KINGDOM (Coventry, London, Oxford, Sheffield)

3 Steps..

1. Sarcoma Centre, 3rd Department of Medicine, University of Athens, Sotiria General Hospital



2. Hellenic Company of Sarcoma

3. ...

Create a sarcoma patient advocacy group..

Listen the patient

“There is only one cardinal rule: one must always listen to the patient”

Oliver Sacks

(Neurologist, author)

1933-2015

Listen your patient..



- *Listen his/her worries*
- *To understand what the patient needs*
- *To set together the ideal goal*
- *To personalize treatment*

**..to achieve the optimal outcome for
the patient**





Thank you..

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