

The SELNET Project

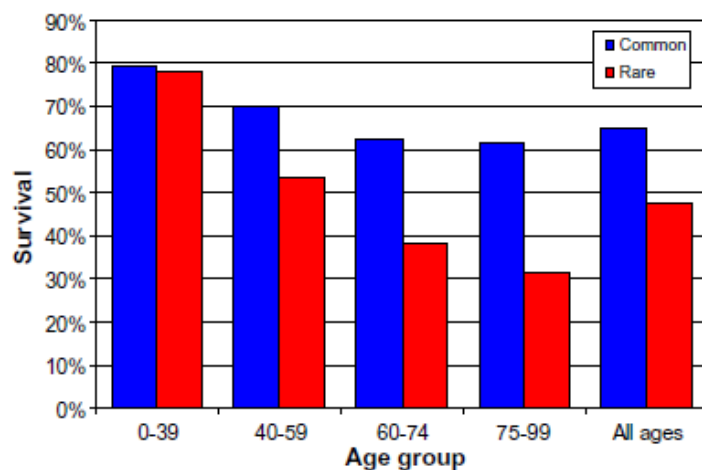
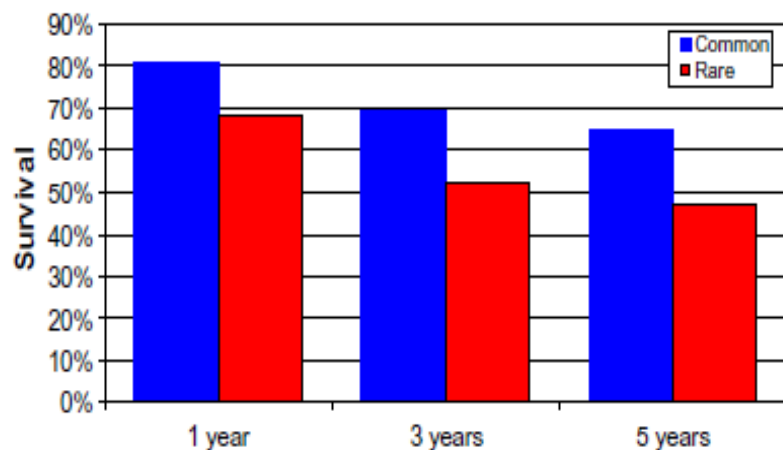


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KEY ISSUES OF POOR OUTCOME OF RARE TUMORS

- Difficulties or delay in diagnostic procedure
- Limited Access to centers with clinical expertise in Rare Cancer
- Inadequate funding for clinical research programmes
- Few interest of Pharma Companies in clinical research programmes



LOWER SURVIVAL

HOW TO OVERCOME THESE CHALLENGES?



Annals of Oncology 30: 1143–1153, 2019
doi:10.1093/annonc/mdz124
Published online 9 April 2019

ORIGINAL ARTICLE

Surgery in reference centers improves survival of sarcoma patients: a nationwide study

J.-Y. Blay^{1,2,3*}, C. Honoré⁴, E. Stoeckle⁵, P. Meeus^{1,2,3}, M. Jafari^{6,7}, F. Gouin^{1,2,3,8,9}, P. Anract¹⁰, G. Ferron¹¹, A. Rochwerger¹², M. Ropars^{13,14}, S. Carrere¹⁵, F. Marchal¹⁶, F. Sirveaux¹⁶, A. Di Marco¹⁷, L. R. Le Nail¹⁸, J. Guiramand¹⁹, G. Vaz^{1,2,3}, J.-C. Machiavello²⁰, O. Marco²¹, S. Causeret²², P. Gimbergues²³, F. Fiorenza²⁴, L. Chaigneau²⁵, F. Guillemin²⁶, J.-M. Guilloit²⁷, F. Dujardin²⁸, J.-P. Spano²⁹, J.-C. Ruzic³⁰, A. Michot⁴, P. Soibinet²⁶, E. Bompas^{8,9}, C. Chevreau¹¹, F. Duffaud¹², M. Rios^{13,14}, C. Perrin^{13,14}, N. Firmin¹⁵, F. Bertucci¹⁹, C. Le Pechoux⁴, F. Le Loarer⁴, O. Collard^{1,2,3}, M. Karanian-Philippe^{1,2,3}, M. Brahmi^{1,2,3}, A. Dufresne^{1,2,3}, A. Dupré^{1,2,3}, F. Ducimetière^{1,2,3}, A. Giraud¹⁰, D. Pérol^{1,2,3}, M. Toulmonde⁵, I. Ray-Coquard^{1,2,3}, A. Italiano⁵, A. Le Cesne⁴, N. Penel^{6,7} & S. Bonvalot³¹, on behalf of the NETSARC/REPPS/RESOS and French Sarcoma Group–Groupe d'Etude des Tumeurs Osseuses (GSF-GETO) Networks[†]

EXPERTISE IS ESSENTIAL

RESEARCH ARTICLE

Open Access

Clinicians' adherence versus non adherence to practice guidelines in the management of patients with sarcoma: a cost-effectiveness assessment in two European regions

Lionel Perrier^{1*}, Alessandra Buja², Giuseppe Mastrangelo³, Antonella Vecchiato⁴, Paolo Sandonà⁵, Françoise Ducimetière⁶, Jean-Yves Blay⁷, François Noël Gilly⁸, Carole Siani⁹, Pierre Biron¹⁰, Dominique Ranchère-Vince¹¹, Anne-Valérie Decouvelaere¹², Philippe Thiesse¹³, Christophe Bergeron¹⁴, Angelo Paolo Dei Tos¹⁵, Jean-Michel Coindre¹⁶, Carlo Riccardo Rossi¹⁷ and Isabelle Ray-Coquard¹⁸

HOW TO OVERCOME THESE CHALLENGES?



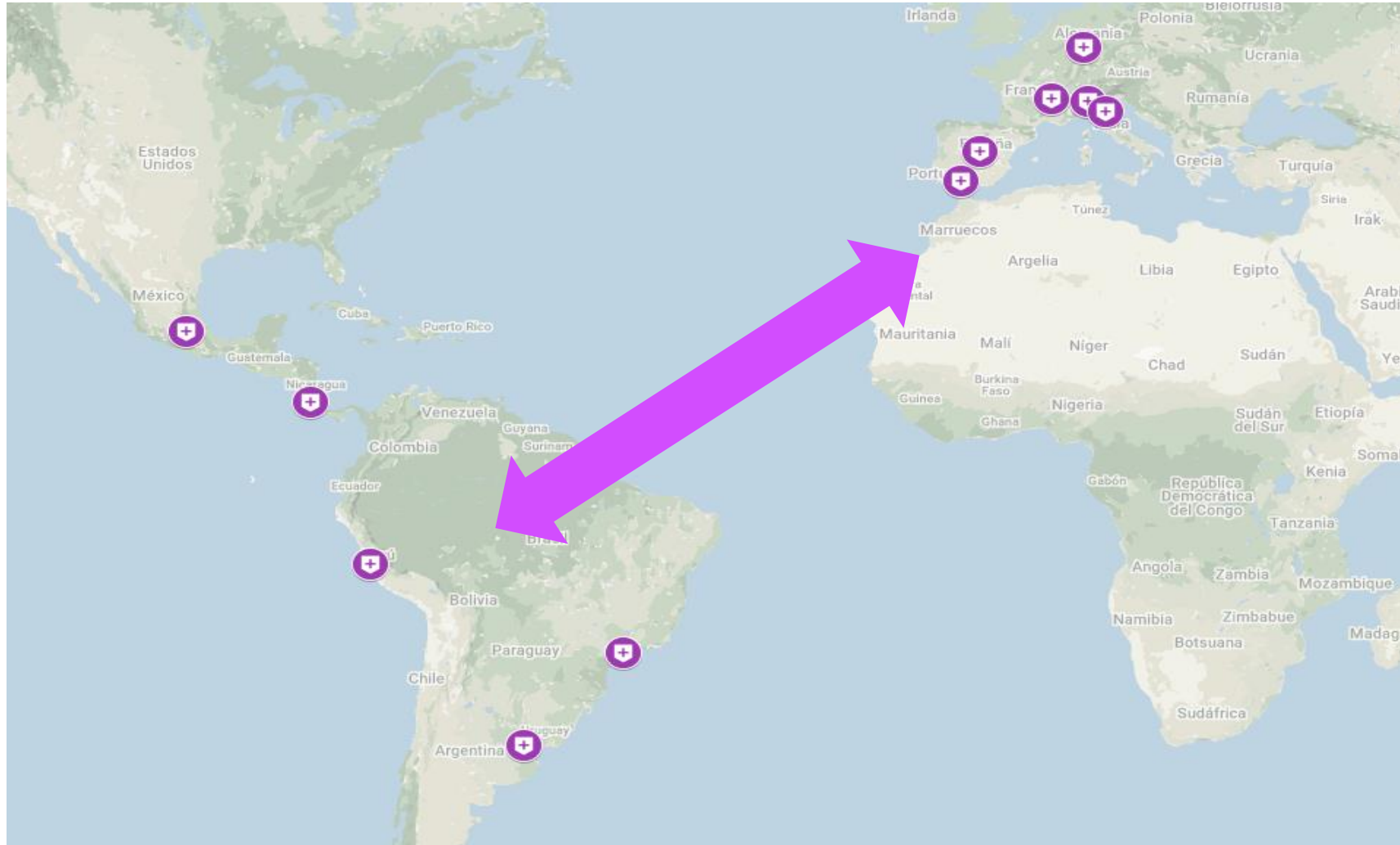
EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES
Share. Care. Cure.



NETWORKING!!!!



COULD WE USE OUR EXPERIENCE TO HELP OTHERS?



SELNET PROJECT



Horizon 2020 Call: H2020-SC1-BHC-2018-2020 (Better Health and care, economic growth and sustainable health systems)

Sarcoma European & Latinamerican NETwork



Funding from the European Commission from 1st January 2019

SELNET PARTNERS



INCAM (**Jorge Luis Martínez Tlahuel**)
Centro Médico Nacional 20 Nov (**Arturo Pavel Miranda Aguirre**)



AC CAMARGO CANCER CENTER (**Celso Mello**)



INSTITUTO ALEXANDER FLEMING (**Matías Chacón**)



INSTITUTO NACIONAL DE ENF NEOPLÁSICAS
(**Víctor Castro Oviden**)



FUNDAEVI (**Natalia Jimenez Brenes**)



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(**Paolo Casali et al**)
ISTITUTO ORTOPEDICO RIZZOLI
(**Piero Picci et al**)



CENTRE LEON BERARD (**Jean-Yves Blay**)



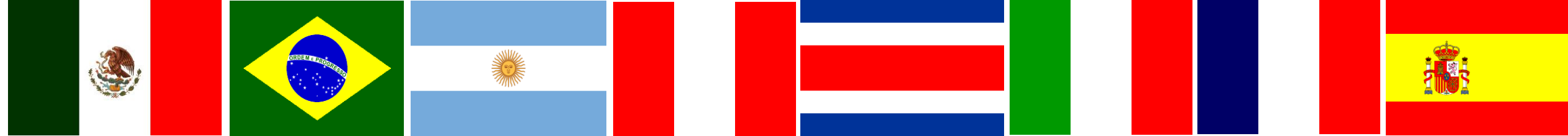
UNIVERSITY H VIRGEN DEL ROCÍO
(**Javier Martin-Broto et al**)

+ 30 ASSOCIATED CENTERS



Sarcoma
Patients
EuroNet



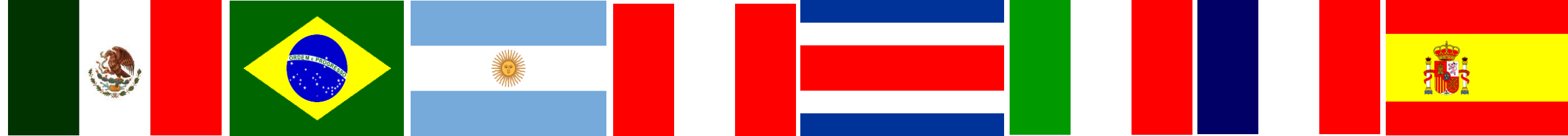


AIMS



- TO IMPROVE CLINICAL OUTCOME in Sarcoma Care
- TO BUILD A NETWORK of REFERENCE CENTERS in Sarcoma Care in different Countries of CELAC
- TO MAKE the NETWORK SUSTAINABLE
- TO VALIDATE a COLLABORATIVE MODEL REPLICABLE IN OTHER RARE TUMORS





VALUES

- High commitment
- Solidarity
- Transparency
- Team working
- Patient-oriented
- Scientific view
- Respect with EU & CELAC rules



WORK PACKAGES



WP Number ⁹	WP Title	Lead beneficiary ¹⁰
WP1	Ethics requirements	1 - SAS
WP2	Definition of reference centers	2 - INT
WP3	Analysis of healthcare barriers	5 - INCAN
WP4	Clinical practice guidelines	4 - CLB
WP5	Continuing medical education	10 - GEIS
WP6	Multidisciplinary review of clinical cases	1 - SAS
WP7	Clinical management quality study	10 - GEIS
WP8	Translational research program	1 - SAS
WP9	Dissemination and exploitation of results	7 - IAF + SPAEN
WP10	Project management	1 - SAS

WP 2 DEFINITION OF REFERENCE CENTERS (RC)



- Consensus of the MINIMUM QUALITY REQUIREMENTS for a Reference Center
- Create a DIAGNOSTIC PATHOLOGY NETWORK (In each Country)
- To ESTABLISH a LATIN AMERICAN SARCOMA NETWORK

	Angelo Paolo Dei Tos, Pathologist network coordinator – University of Padua, Italy.
	Guido Lutter – Institute Alexander Fleming, Argentina.
	Martina Nesprias – General Hospital of Agudos Carlos G. Durand, Argentina.
	Antonio Nascimento – A. C. Camargo Cancer Center, Brazil.
	Felipe d'Almeida Costa – A. C. Camargo Cancer Center, Brazil.
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	Alexandra Meurgey – Léon-Bérard Cancer Center, France.
	François Le Loarer – Bergonié Institute, France.
	Marie Karanian – Léon-Bérard Cancer Center, France.
	Alberto Righi – Rizzoli Orthopedic Institute, Italy.
	Paola Collini – IRCCS National Cancer Institute, Italy.
	Claudia Haydee Sarai Caro Sánchez – National Cancer Institute, Mexico.
	Hugo Ricardo Domínguez Malagón – National Cancer Institute, Mexico.
	Lourdes Huanca – National Cancer Institute of Peru, Peru.
	Sandro Ángel Aníbal Casavilca Zambrano – INEN, Peru.
	Cleofé Romagosa – Vall d'Hebron University Hospital, Spain.
	Enrique de Álava – Virgen del Rocío University Hospital, Spain.
	Rafael Ramos – Son Espases University Hospital, Spain.

WP 3 ANALYSIS OF HEALTHCARE BARRIERS



- Identification of main healthcare barriers
- Action plan to overcome these barriers
- BENEFIT SARCOMA PATIENTS IN LATINOAMERICA

WP 4 CLINICAL PRACTICE GUIDELINES (CPGs)



9th January 2020

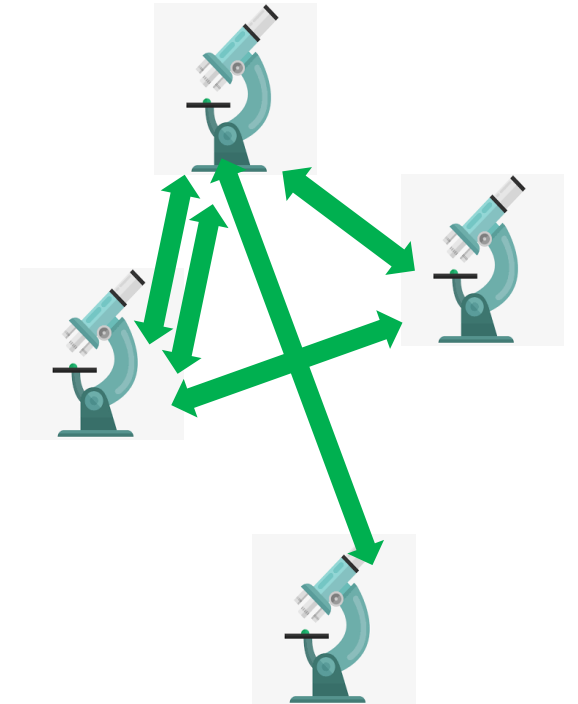
SPAEN representative: Berdn Kasper

Consensus adoption

WP 6 MULTIDISCIPLINARY REVIEW OF CLINICAL CASES



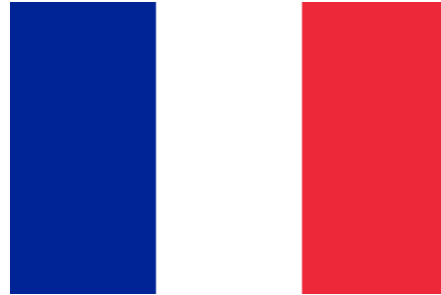
- OBJ 1: To perform peer reviews of pathologic diagnosis
- OBJ 2: To conduct multidisciplinary tumor boards (MDT) to review clinical cases



WP 8 – Translational research program



Desmoplastic small-
round-cell tumor



Angiosarcoma



Extraskelletal Myxoid
Chondrosarcoma



Solitary Fibrous Tumor

We aim to stimulate sarcoma research in CELAC

PROPOSALS FOR ACADEMIC CLINICAL TRIALS

OUR WEBSITE: <https://selnet-h2020.org>



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WELCOME TO SELNET PROJECT

Sarcoma as a model to improve diagnosis and clinical care of rare tumors
through a European and Latin American multidisciplinary network

OUR MEETINGS

IBiS
INSTITUTO DE BIOMEDICINA DE SEVILLA

SEVILLE, FEB 2019



MEXICO DF, SEPT 2019



LYON, JANUARY 2020





THE ROLE OF SPAEN IN SELNET: THE PATIENTS' VOICE

- DISSEMINATION of SELNET
- Information for sarcoma patient in Latinamerica

**YOUR HELP IS ESSENTIAL FOR THE
SUCCESS OF SELNET**

- Helping in the creation and networking of LATAM advocacy groups
- Promoting the need of clinical research
- Approaching healthcare providers and regulators (KEY!!!)



Patients
EuroNet

THANK YOU FOR YOUR ATTENTION



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EUROPEAN COMMISSION



SELNET has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825806.