



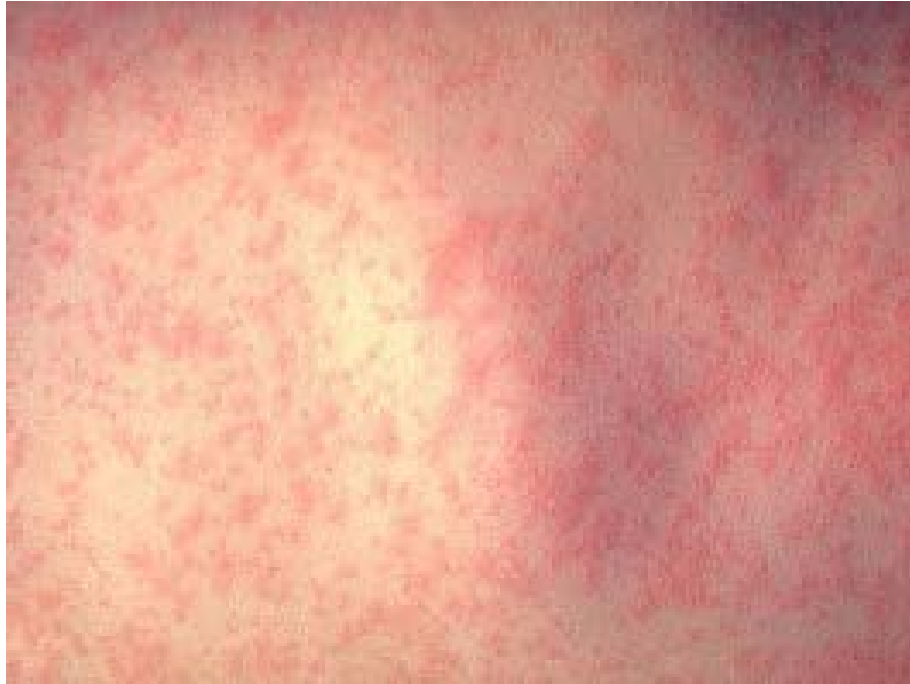
Joining forces for action

A working Consensus on Pathologic diagnosis of Rare Cancers

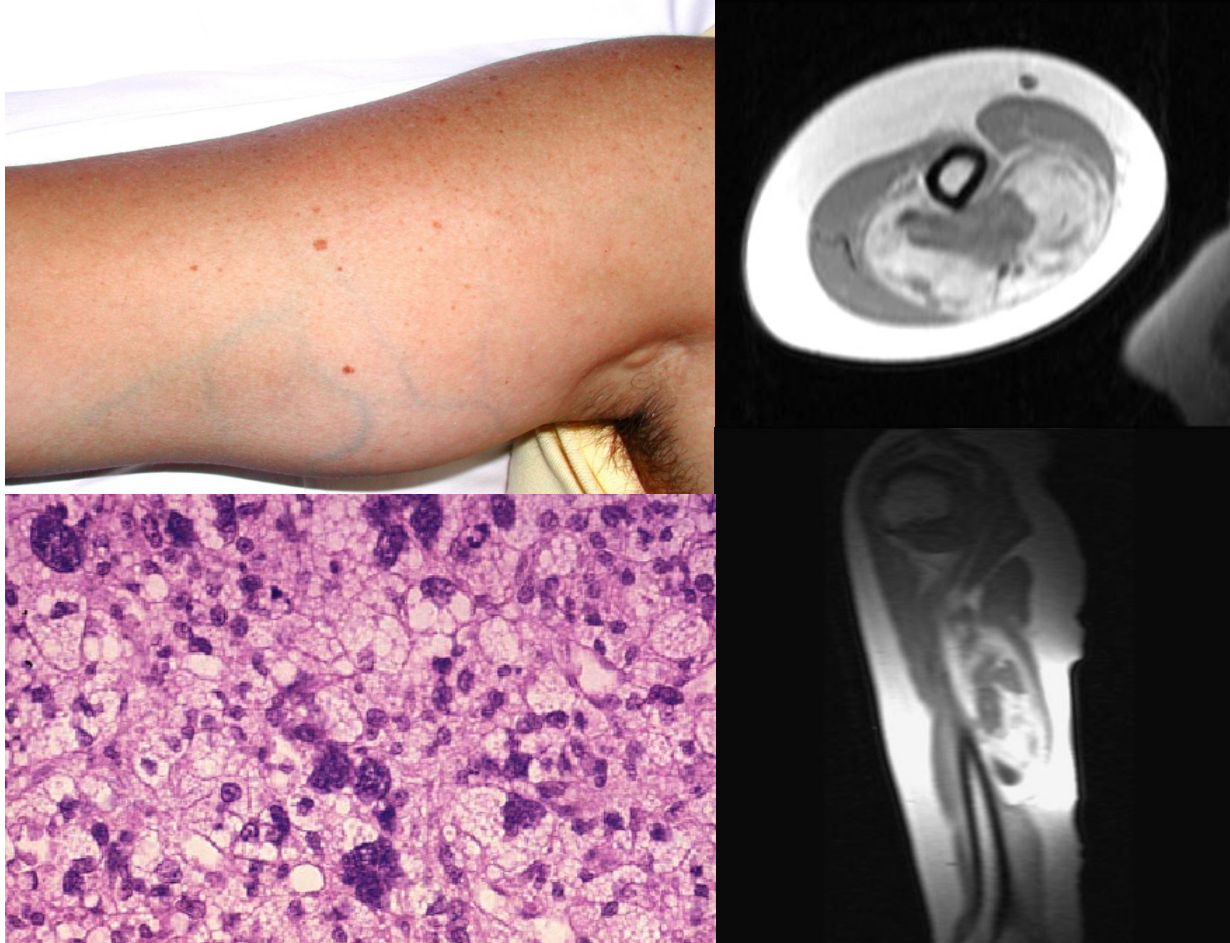
Paolo G. Casali
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The pathologic diagnosis...





measles



liposarcoma

- CARE → lack of clinical expertise
- RESEARCH → lack of numbers for studies
- THERAPY → lack of «market»

Show your support and sign the
Call to Action Against Rare Cancers:

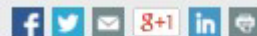
www.rarecancerseurope.org

Rare Cancers Europe is a joint initiative based on a partnership between the European Society for Medical Oncology (ESMO), the European Organisation for Rare Diseases (EURORDIS), the European Cancer Patient Coalition (ECPC), the European Organisation for Research and Treatment of Cancer (EORTC), Conticanet, EuroBoNeT, the World Sarcoma Network (WSN), the Association of European Cancer Leagues (ECL), the Chronic Myeloid Leukaemia Support Group, the International Brain Tumour Alliance (IBTA), Orphanet, the Chronic Myeloid Leukaemia Advocates Network, the Sarcoma Patients EuroNet Association (SPAEN), GIST Support UK & PAWS-GIST, Cancer 52, the International Kidney Cancer Coalition (IKCC), the Chordoma Foundation, the Fondazione IRCCS Istituto Nazionale dei Tumori, the European Institute of Oncology (IEO), the European Society for Paediatric Oncology (SIOP Europe), the European Society of Surgical Oncology (ESSO), the Grupo Español de Tumores Huérfanos e Infrecuentes (GETHI), the European School of Oncology (ESO), the European Oncology Nursing Society (EONS), eCancer, the European Society of Pathology (ESP), the European, Middle Eastern and African Society for Biopreservation and Biobanking (ESBB), Novartis Oncology (initiating sponsor and industry partner), Pfizer Oncology (industry partner), and Sanofi (industry partner). The campaign is moreover supported by additional corporate supporters, including Amgen (silver industry supporter) and Takeda Pharmaceuticals Europe (silver industry supporter).

RARE CANCERS

More common than you think!

Rare Cancers Consensus Meeting: Pathology in Rare Cancers



10 – 11 February 2014, Brussels

Conference Objective: Consensus Statement on Improving Pathological Diagnosis of Rare Cancers

Recommendations stemming from this consensus statement will be crucial in making sure that the Cross-Border Healthcare Directive has the right impact on the lives of patients suffering from rare cancers, through effective use of European Reference Networks.



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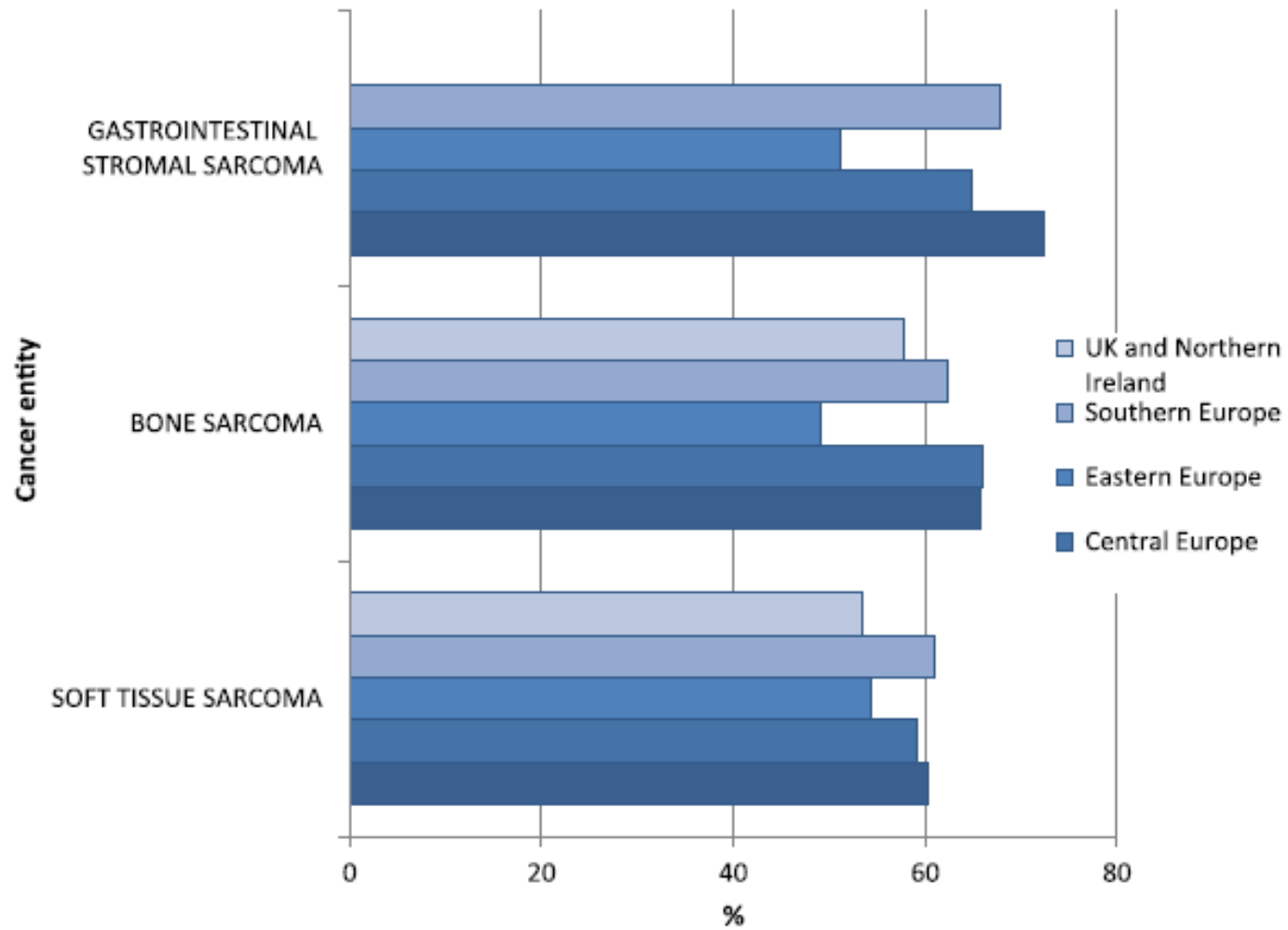
Sarcoma: concordance between initial diagnosis and centralized expert review in a population-based study within three European regions

I. Ray-Coquard^{1,2}, M. C. Montesco³, J. M. Coindre^{4,5}, A. P. Dei Tos⁶, A. Lurkin^{1,2}, D. Ranchère-Vince², A. Vecchiato³, A. V. Decouvlaere², S. Mathoulin-Pélissier^{4,5,7}, S. Albert⁷, P. Cousin², D. Cellier⁸, L. Toffolatti⁶, C. R. Rossi^{3,9} & J. Y. Blay^{2,10} for the Conticanet group

¹University Lyon, EAM 4129 Health Individual Society, Hôtel Dieu, Lyon; ²Centre Léon Bérard, Lyon, France; ³Veneto Institute of Oncology (IOV), IRCCS, Padova, Italy; ⁴University Bordeaux Segalen; ⁵INSERM U916, Bordeaux, France; ⁶General Hospital of Treviso, Italy; ⁷INSERM CIC-EC7 and Clinical and Epidemiological Research Unit, Institut Bergonié, Bordeaux; ⁸Merck Serono, Lyon, France; ⁹University of Padova, Italy; ¹⁰INSERM U590 Cytokine and Cancer, Centre Léon Bérard, Lyon, France

Concordance	Zero	Partial	Full	P
Included tumors ^a	104	515	814	
Type of laboratory				
Public	40 (5%)	241 (32%)	477 (63%)	<0.001
Private	64 (9%)	274 (41%)	337 (50%)	
Included tumors ^b	119	518	820	
Type of tumor sample				
Biopsy	26 (9%)	110 (38%)	154 (53%)	0.47
Surgical specimen	93 (8%)	408 (35%)	666 (57%)	
Included tumors	51	409	449	
Grade				
I	18 (7%)	77 (30%)	164 (63%)	<0.001
II–III	33 (5%)	332 (51%)	285 (44%)	
Included tumors ^c	116	515	821	
Type of sarcoma				
Soft tissue	82 (9%)	323 (36%)	502 (55%)	0.004
Visceral	34 (6%)	192 (35%)	319 (59%)	
Included tumors	121	518	824	
Region				
Aquitaine	34 (10%)	148 (42%)	170 (48%)	<0.001
Rhône-Alpes	65 (10%)	252 (38%)	345 (52%)	
Veneto	22 (5%)	118 (26%)	309 (69%)	
Included tumors	121	518	824	
Subgroup analysis				
SO requested	71 (13%)	263 (47%)	230 (40%)	<0.001
No SO requested	50 (6%)	255 (28%)	594 (66%)	

5-year relative survival for sarcomas (2000-2002)



Stiller CA et al, Eur J Cancer 2013;49:684-95



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Recommendations stemming from this consensus statement will be crucial in making sure that the Cross-Border Healthcare Directive has the right impact on the lives of patients suffering from rare cancers, through effective use of European Reference Networks.



- Referral to expert rare cancer pathologists is crucial for appropriateness
- Networks are the best tool for proper referral
- Multidisciplinary is the best environment for rare cancer patient healthcare



Rare Tumours in Europe CHALLENGES AND SOLUTIONS

6 November 2008 - Brussels

11.15 –13:15 PARALLEL BREAKOUT SESSIONS INCLUDING WORKING LUNCH

Workshop I

Rare tumours: Methodological and Regulatory Challenges

Chair: *Paolo Casali, ESMO* - Co-Chair: *Jan Liliemark, Swedish Medicines Agency*

The orphan drugs approval process - *Filippo De Braud, European Institute of Oncology*

Current guidelines on efficacy assessment in the EU - *Iordanis Gravanis, EMEA*

Strategies for rare tumours in medical statistics - *Paolo Bruzzi, National Institute for Cancer Research of Genoa*

A parliamentary perspective - *Jolanta Dickute, MEP*

Discussion

Workshop II

Rare tumours: Organisational Challenges

Chair: *Jean-Yves Blay, Conticanet* - Co-Chair: *Bertram Wiedenman, Charité University Hospital Berlin*

The challenge of rare tumours treatment in the EU - *Peter Hohenberger, University of Heidelberg*

The role of patient advocacy groups - *Jan Geissler, European Cancer Patient Coalition*

Developing networks in hematology - *Rüdiger Hehlmann, Leukemia Network*

Examples of overcoming the barriers - *Thor Alvegard, Scandinavian Sarcoma Group & Markus Wartenberg, Sarcoma Patients EuroNet*

Discussion

Workshop III

Rare tumours: Patient Access Challenges

Chair: *Kathy Redmond, Cancer World* - Co-Chair: *Flaminia Macchia, Eurordis*

Challenges and barriers: An overview - *Yann Le Cam, Eurordis*

Living with a rare tumour: a patient story - *Ella Pybus, Meningioma UK*

Discussion



Rare Tumours in Europe

CHALLENGES AND SOLUTIONS

6 November 2008 - Brussels

17.

Call for increased integration of local, national and European centres of expertise into European **reference networks**, based on specific criteria as set out in the Commission's proposed Directive on the application of patients' rights in cross-border healthcare , in order to provide the necessary sound organisational structures for more efficient clinical research and early transfer of research data into clinical practice, thus improving the clinical management of rare cancers.

The Value of Banked Samples for Oncology Drug Discovery and Development

Peter M. Shaw, Scott D. Patterson

Correspondence to: Scott D. Patterson, PhD, Medical Sciences, Amgen Inc., One Amgen Center Dr, MS 38-3-A, Thousand Oaks, CA 91320-1799 (e-mail: spatters@amgen.com).

To gain insights into human biology and pathobiology, ready access to banked human tissue samples that encompass a representative cross section of the population is required. For optimal use, the banked human tissue needs to be appropriately consented, collected, annotated, and stored. If any of these elements are missing, the studies using these samples are compromised. These elements are critical whether the research is for academic or pharmaceutical industry purposes. An additional temporal element that adds enormous value to such banked samples is treatment and outcome information from the people who donated the tissue. To achieve these aims, many different groups have to work effectively together, not least of which are the individuals who donate their tissue with appropriate consent. Such research is unlikely to benefit the donors but others who succumb to the same disease. The development of a large accessible human tissue bank resource (National Cancer Institute's Cancer HUman Biobank [caHUB]) that provides an ongoing supply of human tissue for all working toward the common goal of understanding human health and disease has a number of advantages. These include, but are not limited to, access to a broad cross section of healthy and diseased populations beyond what individual collections may achieve for understanding disease pathobiology, therapeutic target discovery, as well as a source of material for diagnostic assay validation. Models will need to be developed to enable fair access to caHUB under terms that enable appropriate intellectual property protection and ultimate data sharing to ensure that the biobank successfully distributes samples to a broad range of researchers.

J Natl Cancer Inst Monogr 2011;42:46-49

DIRECTIVES

**DIRECTIVE 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL
of 9 March 2011
on the application of patients' rights in cross-border healthcare**

EU Reference Networks

- Criteria
- Funding
- Networking



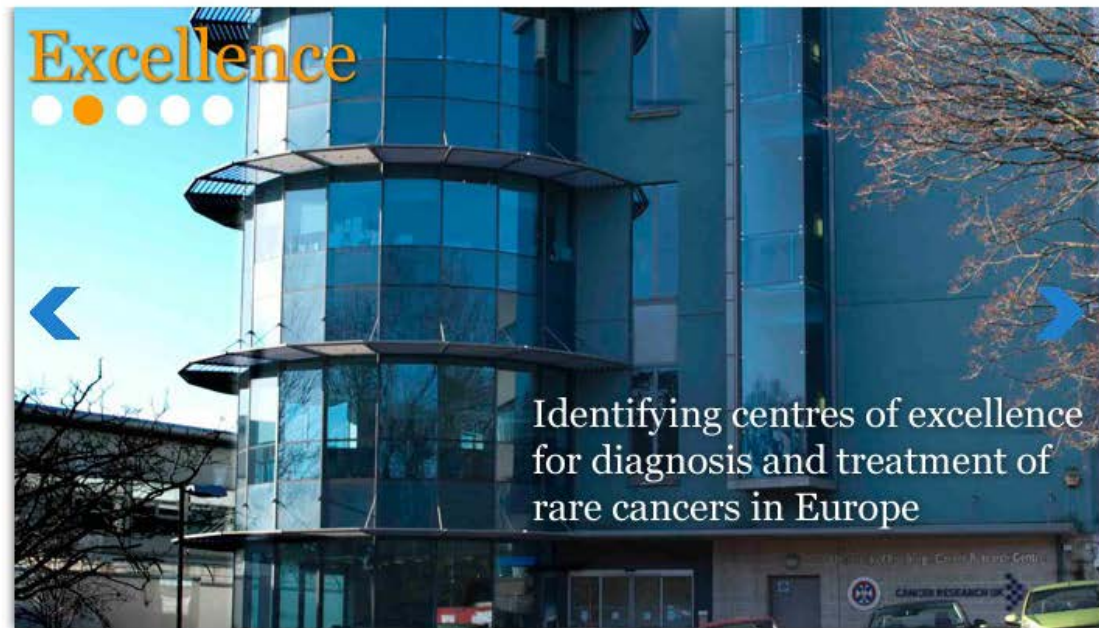


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Information Network on Rare Cancers



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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

Table 1 - Data quality indicators and other characteristics of malignant cancers diagnosed in European cancer registries 1995-2002 and included in the analyses.

Country	Registry	Number of malignant cancers	Data quality indicators					
			Death certificate only (%)	Autopsy (%)	Microscopic verification (%)	Cases 1995-1998 occurred before 5 years (%)	Morphology code ICD ⁹ (%)	Topography code ICD ⁹ (%)
Austria	Austria	306,699	8.9	0.0	85.2	5.9	10.1	0.6
Belgium	Flanders	146,715	0.0	0.2	89.8	0.0	7.3	0.5
	Walloon	11,113	0.0	0.0	95.8	3.3	3.9	0.2
France	Calvados	5895	0.0	0.0	88.1	6.1	2.5	0.3
	Calvados digestive	2861	0.0	0.0	87.0	4.4	10.5	0.3
	Cher d'Or digestive	4376	0.0	0.0	82.8	0.5	17.5	0.2
	Cher d'Or haematol.	1884	0.0	0.0	105.0	7.2	0.0	0.5
	Dordogne	5762	0.0	0.0	95.8	2.1	3.2	0.3
	Haut Rhin	9073	0.0	0.0	95.4	5.8	2.9	0.1
	Hérault	10,305	0.0	0.0	9.0	6.4	1.5	0.1
	Isère	12,026	0.0	0.0	94.1	4.6	4.1	0.1
	Loire Atlantique	3746	0.0	0.0	100.0	6.8	0.0	0.0
	Manche	6267	0.0	0.0	96.5	2.7	3.4	0.3
	Marne and Ardennes	169	0.0	0.0	100.0	3.6	0.0	0.0
	Somme	6481	0.0	0.0	94.2	6.6	5.5	0.8
Yonne	4995	0.0	0.0	93.8	3.0	5.9	1.3	
Germany	Saarland	54,132	3.9	0.0	91.8	5.8	8.0	0.5
Iceland	Iceland	884	0.1	1.4	96.6	0.0	3.5	0.0
Ireland	Ireland	156,529	2.0	0.3	86.7	0.0	11.0	0.7
Italy	Abu Afife	18,076	0.7	0.0	89.5	0.0	9.2	0.5
	Basilicata	11,770	1.3	0.4	87.0	0.0	10.5	0.3
	Calabria	23,760	1.1	0.0	88.1	0.0	9.7	0.6
	Emilia	60,397	0.9	0.1	80.4	0.4	17.7	0.8
	Friuli V.G.	78,887	0.6	1.9	91.0	0.3	9.8	2.1
	Liguria	44,257	1.6	0.0	81.4	0.0	16.6	0.9
	Lombardy	10,886	1.3	0.0	87.4	0.2	13.1	0.6
	Marche	34,949	0.5	0.0	88.6	0.4	11.8	0.5
	Naples	8185	3.9	0.0	73.0	1.9	17.6	1.4
	Piedmont	581	2.2	0.0	92.6	0.0	7.2	0.0
	Puglia	23,886	1.0	0.0	86.0	0.0	10.1	0.7
	Sardinia	10,887	1.9	0.8	80.9	0.1	26.6	0.6
	Trentino	22,052	0.2	0.0	88.1	0.0	13.8	0.5
	Tuscany	60,667	2.4	0.0	87.9	0.1	13.3	0.5
	Umbria	36,917	2.5	0.0	77.5	4.0	23.7	1.1
	Veneto	18,884	2.8	0.2	84.4	0.0	16.4	0.4
	Apulia	17,788	2.0	0.0	85.0	0.3	17.8	0.8
Lazio	45,211	0.7	0.0	84.0	0.1	12.6	0.6	
Marche	24,708	1.1	0.0	88.0	11.5	10.8	0.4	
Veneto	84,028	1.5	0.2	87.5	0.8	13.7	1.7	



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R CANCERS EUROPE E

Joining forces for action



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