

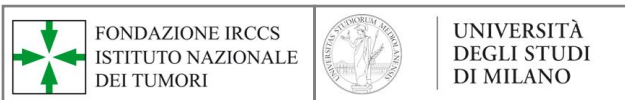
R
CANCERS
EUROPE
E

EURACAN



ERN on adult cancers
(solid tumours)
(ERN EURACAN)

Welcome...



Paolo G. Casali
paolo.casali@istitutotumori.mi.it

DISCLOSURE INFORMATION

Honoraria received for speaker, consultancy or advisory role from Pharma:

Bayer, Blueprint Medicines, Deciphera, Eisai, Eli Lilly, Glaxo, Merck KGAA, Merck Serono, Nektar Therapeutics, Novartis, Pfizer, PharmaMar

Institutional financial support to clinical studies from Pharma to my Unit at Fondazione IRCCS Istituto Nazionale Tumori, Milano, Italy:

Advenchen Laboratories, Amgen Dompé, AROG Pharmaceuticals, Bayer, Blueprint Medicines, Daiichi Sankyo, Deciphera, Eisai, Eli Lilly, Epizyme Inc, Glaxo, Karyopharm Pharmaceuticals, Nektar Therapeutics, Novartis, Pfizer, PharmaMar



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, EuroBioNet, 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!



R CANCERS EUROPE E

Joining forces for action

2018 2008

THE **PARLIAMENT**
POLITICS, POLICY AND PEOPLE **MAGAZINE**

Tuesday 25 September
European Parliament
Room A3E2
12:00 to 14:00

Kindly hosted by
Alojz Peterle, MEP
Lieve Wierinck, MEP

Join the conversation!
@_rarecancer
@Parlimag
#RCE10thanniversary

ESMO GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE



epp
EUROPEAN PARLIAMENT
POLITICS AND POLICY

abde
ASSOCIATION OF
DIAGNOSTIC BIOTECHNOLOGICAL
ENTERPRISES



RARE CANCER AGENDA 2030

Ten Recommendations from the EU Joint Action on Rare Cancers

1. Rare cancers are the rare diseases of oncology
2. Rare cancers should be monitored
3. Health systems should exploit networking
4. Medical education should exploit and serve healthcare networking
5. Research should be fostered by networking and should take into account an expected higher degree of uncertainty
6. Patient-physician shared clinical decision-making should be especially valued
7. Appropriate state-of-the-art instruments should be developed in rare cancer
8. Regulation on rare cancers should tolerate a higher degree of uncertainty
9. Policy strategies on rare cancers and sustainability of interventions should be based on networking
10. Rare cancer patients should be engaged

RARE CANCER AGENDA 2030

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RARE CANCER AGENDA 2030 Ten Recommendations from the EU Joint Action on Rare C

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5.3 Methodological solutions.

- 5.3.1 The principle that a higher degree of uncertainty needs to be tolerated in rare cancers should be acknowledged in selecting the methodology of new clinical studies. In general, clinical studies should also be done when a lower statistical precision is likely, given available numbers, and their patient populations should be selected exclusively to maximize the chances of any new treatment to display its maximum efficacy, without widening eligibility criteria inappropriately. Even the study duration should be reasonable, given available numbers.

RARE CANCER AGENDA 2030

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3. Health systems should exploit networking...

...around multidisciplinary centres of reference, to improve quality of care in rare cancers by rationalizing patient access to available best expertise and lowering/rationalizing health migration

EURACAN



EuroBloodNet



**European
Reference
Network**

for rare or low prevalence
complex diseases

⊗ **Network**
Paediatric Cancer
(ERN PaedCan)



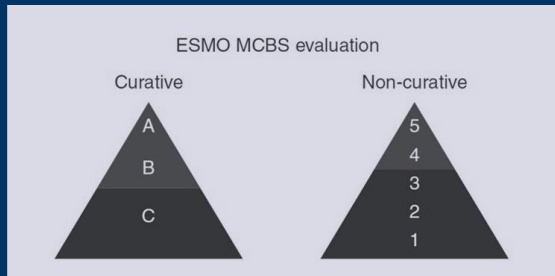
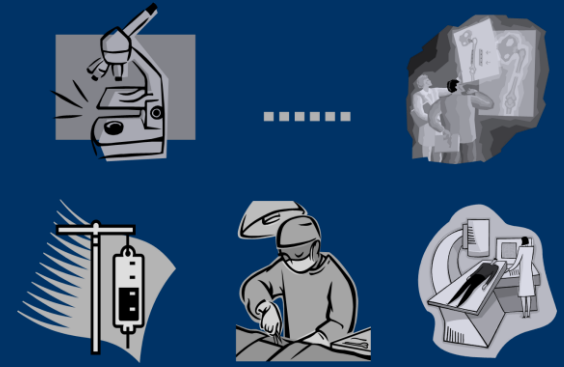
**European
Reference
Network**

for rare or low prevalence
complex diseases

⊗ **Network**
Genetic Tumour Risk
Syndromes (ERN GENTURIS)

Clinical practice guidelines





(adapted from the Infectious Diseases Society of America-United States Public Health Service Grading System²)

Levels of evidence

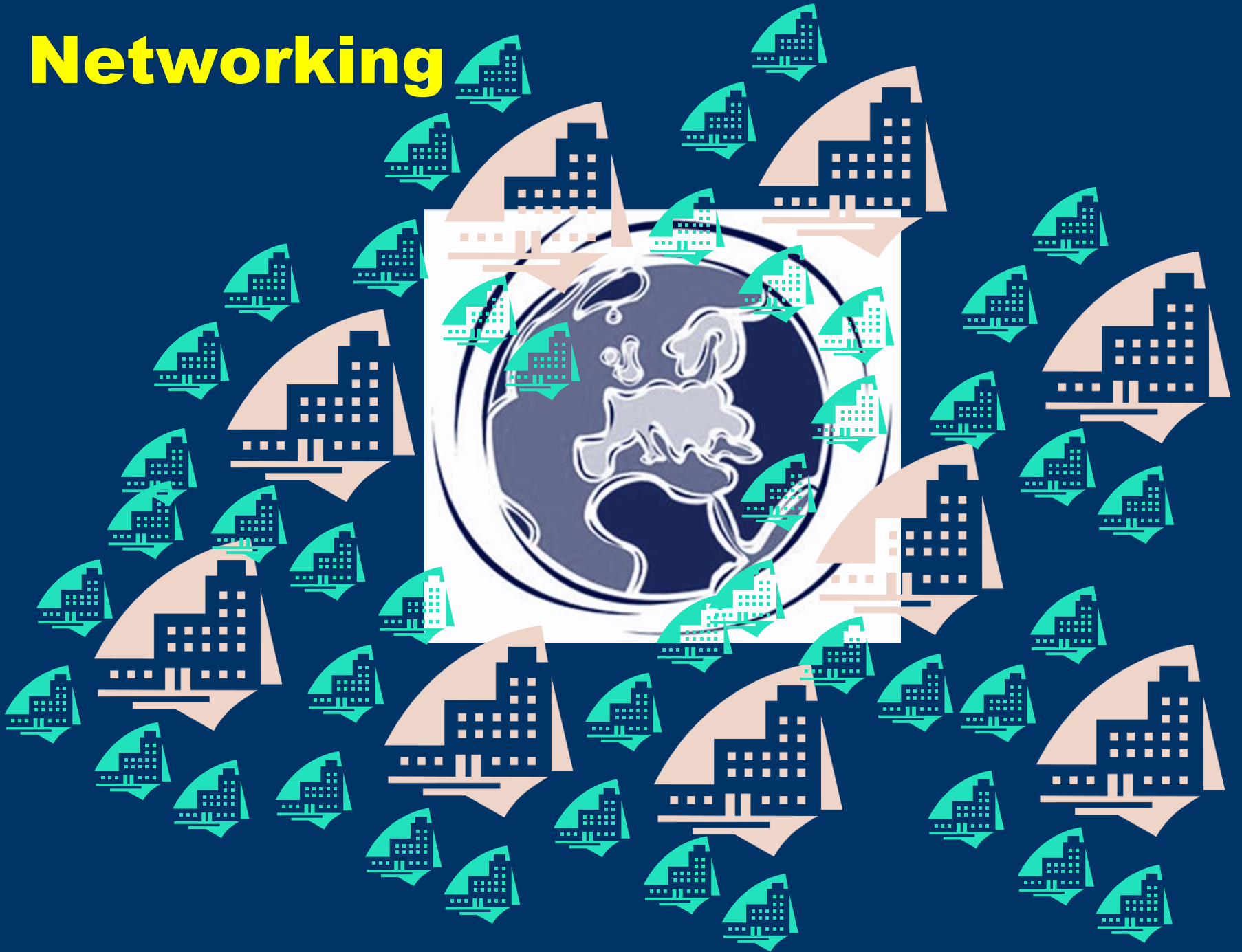
- I Evidence from at least one large, randomised, controlled trial of good methodological quality (low potential for bias) or meta-analyses of well-conducted, randomised trials without heterogeneity
- II Small, randomised trials or large, randomised trials with a suspicion of bias (lower methodological quality) or meta-analyses of such trials or of trials with demonstrated heterogeneity
- III Prospective cohort studies
- IV Retrospective cohort studies or case-control studies
- V Studies without the control group, case reports, experts opinions

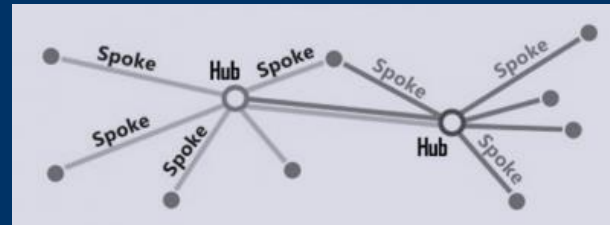
Grades of recommendation

- A Strong evidence for efficacy with a substantial clinical benefit, strongly recommended
- B Strong or moderate evidence for efficacy but with a limited clinical benefit, generally recommended
- C Insufficient evidence for efficacy or benefit does not outweigh the risk or the disadvantages (adverse events, costs, ...), optional
- D Moderate evidence against the efficacy or for adverse outcomes, generally not recommended
- E Strong evidence against the efficacy or for adverse outcomes, never recommended

²By permission of the Infectious Diseases Society of America [163].

Networking





The «network patient»...



Medical education



Rare cancers



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 Licita ^f, Sandra Mallone ^g, Andrea Tavilla ^g, Annalisa Trama ^a, Riccardo Capocaccia ^g, The RARECARE working group

Eur J Cancer 2011;47:2493

Table 3 - 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 (retained before 1 year) (%)	Morphology code ICD-O ² (%)	Topography code ICD-O ² (%)
Austria	Austria	304,480	8.9	0.0	85.2	5.9	10.1	0.6
Belgium	Flanders	144,725	0.0	0.2	99.8	0.0	7.3	0.5
France	Bas Rhin	13,133	0.0	0.0	95.8	3.3	3.9	0.2
	Calvados	5895	0.0	0.0	96.1	4.1	2.5	0.3
	Calvados Digestive	3803	0.0	0.0	87.0	4.4	10.5	0.3
	Cluse d'Or digestive	4376	0.0	0.0	82.8	0.5	17.5	0.2
	Cluse d'Or haematol.	1884	0.0	0.0	100.0	7.3	0.0	0.5
	Doubs	5742	0.0	0.0	95.8	2.1	3.2	0.3
	Haut Rhin	9073	0.0	0.0	96.4	5.8	3.9	0.1
	Hersault	10,305	0.0	0.0	0.0	4.4	1.5	0.1
	Jura	12,524	0.0	0.0	94.1	4.8	4.1	0.1
	Loire Atlantique	3746	0.0	0.0	100.0	6.8	0.0	0.0
	Maine	6287	0.0	0.0	96.5	7.7	3.4	0.3
	Marne and Ardennes	198	0.0	0.0	100.0	3.6	0.0	0.0
	Somme	6485	0.0	0.0	94.2	6.6	0.0	0.0
	Tarn	4935	0.0	0.0	93.8	7.0	5.9	1.3
Germany	Saarland	54,322	1.9	0.0	91.8	5.8	8.0	0.5
Ireland	Ireland	8854	0.1	1.4	96.6	0.0	3.5	0.0
Ireland	Ireland	150,529	3.0	0.3	86.7	0.0	11.0	0.7
Italy	Abu Adige	18,076	0.7	0.0	89.5	0.0	9.2	0.5
	Belluno	13,770	1.3	0.4	87.0	0.0	10.5	0.3
	Ferrara	23,740	1.1	0.0	88.1	0.4	9.7	0.6
	Frosino	66,097	0.9	0.1	80.4	0.4	17.7	0.8
	Frank VIC	78,802	0.4	1.9	94.0	0.4	9.4	2.1
	Genova	44,207	1.8	0.0	81.4	0.0	36.6	0.9
	Mantova	102,364	1.3	0.0	87.4	0.2	13.1	0.6
	Modena	34,947	0.5	0.0	88.6	0.4	11.8	0.5
	Napoli	8345	3.9	0.0	73.0	1.9	17.6	1.4
	Palermo	585	2.2	0.0	92.6	0.0	7.2	0.0
	Pavia	23,826	1.0	0.0	86.0	0.3	13.1	0.7
	Reggio Emilia	60,667	1.9	0.0	86.9	0.1	16.9	0.5
	Reggio Emilia	23,152	0.7	0.0	88.1	0.0	13.8	0.5
	Rovigo	60,667	2.4	0.0	87.9	0.1	17.9	0.5
	Salsomaggiore	26,917	2.5	0.0	77.5	4.0	20.7	1.1
	Savona	18,084	3.9	0.2	84.4	0.0	36.4	0.7
	Taranto	12,788	2.0	0.0	85.0	0.1	17.9	1.8
	Udine	45,321	0.7	0.0	84.0	0.1	12.6	0.6
	Varese	24,728	1.1	0.0	89.8	1.1	10.8	0.8
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- Pediatric cancers
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Rare adult solid cancers



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 Licita ^f, Sandra Mallone ^g, Andrea Tavilla ^g, Annalisa Trama ^a, Riccardo Capocaccia ^g, The RARECARE working group

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Rare adult solid cancers

- **Pediatric cancers**
- **Haematologic rare neoplasms**
- **Sarcomas**
- **Rare thoracic cancers**
- **Neuroendocrine tumours**
- **Head & neck cancers**
- **Central nervous system tumours**
- **Rare female genital cancers**
- **Rare urological and male genital tumours**
- **Endocrine gland tumours**
- **Digestive rare cancers**
- **Rare skin cancers & non-cutaneous melanoma**



Rare adult solid cancers



2-yr training path for clinical oncologists

- **Clinical Update on adult solid RCs** *yearly*
- **Introduction to RCs** *1 w*
- **10 Training courses** *online*
- **Clinical Fellowships** *6-9 mos*
- **Curriculum & Examination**



ONLINE EVENT

5TH ESO-ESMO-RCE CLINICAL UPDATE ON RARE ADULT SOLID CANCERS

PRE-RECORDED SESSIONS:
from 1 December 2020

LIVE SESSIONS:
16-17 January 2021

Chairs: J.Y. Blay, FR - P.G. Casali, IT - R.A. Stahel,

**REGISTRATION FOR THE EVENT IS FREE BUT MANDATORY.
FURTHER INFORMATION AVAILABLE AT WWW.ESO.NET AND WWW.E-ESO.NET**

Held in collaboration with



Sistema Socio Sanitario



In partnership with



European
Reference
Network

for rare or low prevalence
complex diseases

Network
Adult Cancers
(ERN EURACAN)

THE JOINT ACTION ON RARE CANCERS: WHAT NEXT?

Pre-recorded sessions available **from 1 December 2020**

Moderators: J.Y. Blay, FR - F.A. Peccatori, IT

- The rare cancer agenda 2030
- The epidemiology of rare adult solid cancers
- EURACAN: where we are?
- An educational pathway on rare adult solid cancers

P.G. Casali, IT
A. Trama, IT
J.Y. Blay, FR
A.M. Frezza, IT

UPDATE ON RARE THORACIC CANCERS

Pre-recorded sessions available **from 1 December 2020**

Moderators: M. Garassino, IT - R.A. Stahel, CH

- Mesothelioma
- Thymic tumors

R.A. Stahel, CH
M. Garassino, IT

UPDATE ON SARCOMAS

Pre-recorded sessions available **from 1 December 2020**

Moderators: J.Y. Blay, FR - P.G. Casali, IT

- Adult soft tissue sarcomas
- GIST
- Ewing sarcoma and osteosarcoma
- Rare bone and soft tissue sarcomas
- Improving the surgical margin in sarcomas

P.G. Casali, IT
J.Y. Blay, FR
S. Strauss, GB
S. Stacchiotti, IT
A. Gronchi, IT

UPDATE ON HEAD AND NECK CANCERS

Pre-recorded sessions available **from 1 December 2020**

Moderators: V. Gregoire, FR - L. Licitra, IT

- Laryngeal & hypopharyngeal carcinoma
- Oropharyngeal carcinoma
- Nasopharyngeal carcinoma & sinonasal cancers
- Salivary gland tumors
- Oral cavity tumors
- Advances in molecular biology

C. Piazza, IT
V. Gregoire, FR
L. Licitra, IT
L.D. Locati, IT
C. Simon, CH
L. De Cecco, IT

UPDATE ON NEUROENDOCRINE TUMORS

Pre-recorded sessions available **from 1 December 2020**

Moderators: M. Caplin, GB - F. De Braud, IT

- Thoracic NETs
- Gastroenteropancreatic NETs

M. Caplin, GB
N. Fazio, IT

UPDATE ON CNS TUMORS

Pre-recorded sessions available **from 1 December 2020**

Moderators: R. Soffietti, IT - M.J. Van den Bent, NL

- Gliomas
- Rare CNS tumors
- Hereditary cancer risk syndromes

R. Soffietti, IT
M.J. Van den Bent, NL
J. Balmana, ES

UPDATE ON ENDOCRINE GLAND TUMORS

Pre-recorded sessions available **from 1 December 2020**

Moderators: C. de la Fouchardiere, FR - L. Licitra, IT

- Adrenal cancer
- Thyroid cancer
- The epidemiological evidence of sovradiagnosis

A. Berruti, IT
J. Capdevila, ES
S. Franceschi, IT

UPDATE ON DIGESTIVE RARE CANCERS

Pre-recorded sessions available **from 1 December 2020**

Moderators: F. De Braud, IT - L. Wyrwicz, PL

- Biliary tumors
- Anal carcinoma
- Peritoneal mesothelioma & pseudomyxoma

H.J. Klumpen, NL
R. Glynne-Jones, GB
M. Deraco, IT

UPDATE ON RARE UROGENITAL CANCERS

Pre-recorded sessions available **from 1 December 2020**

Moderators: J.A. Gietema, NL - A. Necchi, IT

- Testicular cancer
- Penile cancer
- Survivorship as a healthcare issue
- Survivorship as a clinical issue

J.A. Gietema, NL
A. Necchi, IT
T. Albrecht, SI
R. Ladenstein, AT

UPDATE ON RARE FEMALE GENITAL CANCERS

Pre-recorded sessions available **from 1 December 2020**

Moderators: F.A. Peccatori, IT - M. Seckl, GB

- Non-epithelial ovarian tumors
- Trophoblastic tumors
- Vulvar and vaginal cancers

I. Ray-Coquard, FR
M. Seckl, GB
D. Lorusso, IT

UPDATE ON RARE SKIN TUMORS AND UVEAL MELANOMA

Pre-recorded sessions available **from 1 December 2020**

Moderators: E. Kapiteijn, NL - S. Piperno-Neumann, FR

- Merkel cell carcinoma
- Cutaneous adnexal malignancies
- Uveal melanoma

C. Lebbé, FR
S. Cavalieri, IT
M. Angi, IT

In partnership with



Saturday, 16 January

LIVE SESSION - THE JOINT ACTION ON RARE CANCER: WHAT NEXT?

Moderators: F.A. Peccatori, IT - R.A. Stahel, CH

- 11:30 Introduction
11:40 Round table: The Rare Cancer Agenda 2030
- 12:10 Q&A and General discussion
- FA. Peccatori, IT - R.A. Stahel, CH
J.Y. Blay, FR - P.G. Casali, IT
F. De Lorenzo, IT - K. Oliver, GB
FA. Peccatori, IT - A. Trama, IT

LIVE SESSION - UPDATE ON RARE THORACIC CANCERS

Moderators: M. Garassino, IT - R.A. Stahel, CH

- 12:40 Q&A
13:00 Clinical case discussion
- M. Garassino, IT - R.A. Stahel, CH

LIVE SESSION - UPDATE ON SARCOMAS

Moderators: J.Y. Blay, FR - P.G. Casali, IT

- 13:30 Q&A
13:50 Clinical case discussion
- J.Y. Blay, FR - P.G. Casali, IT
A. Gronchi, IT - S. Stacchiotti, IT
S. Strauss, GB
A.M. Frezza, IT

LIVE SESSION - UPDATE ON HEAD & NECK CANCERS

Moderators: V. Gregoire, FR - L. Licitra, IT

- 14:15 Q&A
14:35 Clinical case discussion
- L. De Cecco, IT - Vt Gregoire, FR
L. Licitra, IT - L.D. Locati, IT
C. Piazza, IT - C. Simon, CH
C. Resteghini, IT

LIVE SESSION - UPDATE ON NEUROENDOCRINE TUMORS

Moderators: M. Caplin, GB - F. De Braud, IT

- 15:00 Q&A
15:20 Clinical case discussion
- M. Caplin, GB - F. De Braud, IT
N. Fazio, IT

LIVE SESSION - UPDATE ON CNS TUMORS

Moderators: R. Soffiotti, IT - M.J. Van den Bent, NL

- 15:45 Q&A
16:05 Clinical case discussion
- J. Balmana, ES - R. Soffiotti, IT
M.J. Van den Bent, NL

Sunday, 17 January

LIVE SESSION - UPDATE ON ENDOCRINE GLAND TUMORS

Moderators: C. de la Fouchardiere, FR - L. Licitra, IT

- 11:30 Q&A
11:50 Clinical case discussion
- A. Berruti, IT - J. Capdevila, ES
C. de la Fouchardiere, FR
S. Franceschi, IT - L. Licitra, IT

LIVE SESSION - UPDATE ON DIGESTIVE RARE CANCERS

Moderators: F. De Braud, IT - L. Wyrwicz, PL

- 12:15 Q&A
12:35 Clinical case discussion
- F. De Braud, IT - M. Deraco, IT
R. Glynn-Jones, GB
H.J. Klumpen, NL - L. Wyrwicz, PL
M. Niger, IT

LIVE SESSION - UPDATE ON RARE UROGENITAL CANCERS

Moderators: J.A. Gietema, NL - A. Necchi, IT

- 13:00 Q&A
13:20 Clinical case discussion
- T. Albrecht, SI - J.A. Gietema, NL
R. Ladenstein, AT - A. Necchi, IT

LIVE SESSION - UPDATE ON RARE FEMALE GENITAL CANCERS

Moderators: F.A. Peccatori, IT - M. Seckl, GB

- 13:45 Q&A
14:05 Clinical case discussion
- D. Lorusso, IT - FA. Peccatori, IT
I. Ray-Coquard, FR - M. Seckl, GB

LIVE SESSION - UPDATE ON RARE SKIN TUMORS & UVEAL MELANOMA

Moderators: E. Kapiteijn, NL - S. Piperno-Neumann, FR

- 14:30 Q&A
14:50 Clinical case discussion
15:05 **Closing remarks**
- M. Angi, IT - S. Cavalieri, IT
E. Kapiteijn, NL - C. Lebbé, FR
S. Piperno-Neumann, FR
P.G. Casali, IT

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