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In memory of our dear Thomas

On behalf of the OEI
Mahasti Saghatchian
Gustave Roussy

Prof. Thomas Tursz at First Edition
of the OEI Oncology Days
Genoa, 2008



The European cancer community has lost one of its most outstanding oncologists and researcher: our dearest Professor Thomas Tursz passed away on Friday, April 27 at the age of 71.

Thomas was born in Krakow in 1946 and his father, who was a doctor of the Warsaw ghetto, left Poland for France after the War. He brilliantly became a medical doctor in 1972, specialising in medical oncology and completed his training as PhD in 1977, and was appointed Professor of Oncology at University Paris-Sud in 1986.

An innovative doctor and scientist, he was director of the CNRS 'Tumor Biology' unit from 1984 to 1996, and leader of Medical Oncology at Institut Gustave Roussy from 1986 to 1994.

With a degree from the Harvard School of Public Health, Boston (USA), he was appointed Director General of the Institute in 1994, a position he held for 16 years until September 2010.

Thomas founded in 1999 the Graduate School of Cancerology at Paris-Sud University, the only thematic Doctoral School dedicated to cancer in France. He was the Director from 1999 to 2010.

He was also President of the French Federation of Comprehensive Cancer Centres (UNICANCER) from 2004 to 2010.

At the European level, Thomas chaired the Scientific Advisory Committee of the EORTC from 2003 to 2010 and was Vice-President of EORTC Board from 2006 to 2009.

As President of the OEI (2002-2005) he led a major transformation of the Organisation in collaboration with Ulrik Ringborg and launched the Accreditation and Designation Program which is one of the major successes of the Organisation and its core activity.

Thomas's scientific career has been extremely prolific with more than 350 publications in peer-reviewed journals (particularly in Nature, Science, PNAS, New England Journal of Medicine, Lancet, and Journal of Clinical Investigation). He was one of the key players in the description of the oncogenic role of the Epstein Barr virus.

In medical oncology, he has been a true visionary having developed the first anti-tumor immunotherapy, gene therapy and launched the first programme of precision medicine. In particular, he created the WIN consortium to develop this precision medicine worldwide. He has contributed profoundly to Gustave Roussy's international reputation for his exceptional ability to identify and attract the best talent, while at the same time leading a restructuring and a modernisation of the institution.

He was awarded numerous international prizes that attest to his extraordinary career: the Cancer Prize of the National Cancer League in 1979, the Bernard-Halpern Immunology Award in 1983, the Cancer Prize of the French Academy of Sciences in 1988, the French Radiation Prize in 2001, the Rosen Oncology Award (Medical Research Foundation) in 1989, the Cancer Research Grand Prix of the Academy of Medicine in 1992, then the prestigious Hamilton Fairley Award for Clinical Research of the European Society of Medical Oncology (ESMO) in 1998. Thomas Tursz was made Knight then Officer in the Order of the Legion of Honor in 2001 and 2014.

Beyond all these medico-scientific achievements, Thomas has been for many of us a model of integrity, intelligence and generosity. His motto "reconcile Science and Humanity" perfectly summarises the intellectual and human need that guided all his work in oncology at the Institut Gustave Roussy and beyond. We are losing a huge model and a great friend.



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The 40th OECl Anniversary Poznań 2018

Dominique de Valeriola
Institut Jules Bordet



“Forty years onwards” could be the title of a famous novel or, better still, in more current terms, a reality in a continuous state of becoming. Being the intuitive brainchild of Professor Umberto Veronesi, the OECl has fulfilled diverse missions over the last forty years and certainly the one of bringing together European cancer centres, these essential actors of the fight against cancer. The European geographical borders have played a fundamental role in defining the mandate of our Organisation. Initially, the OECl carried out an important role in opening a communication channel with fellow colleagues in the former U.S.S.R. Following the fall of the Berlin Wall, the interaction with Central European countries both intensified and became more accessible. In this new, geopolitical backdrop, the OECl initiated a cautious transformation in order to better define what should be its mission and mandate.

Added to the complex process of the OECl's transformation was a modification in 2005 to its actual legal structure, which resulted in the OECl becoming a European Economic Interest Grouping - EEIG, formally recognized by the European Union, and unique amongst the associations operating in the field of oncology and related biomedicine branches.

In the course of the last forty years, a succession of many well-known personalities from Europe's leading oncological circles have presided over the OECl. Here I would like to reminisce about some of our former Presidents, besides Umberto Veronesi, we had Jerzy Einhorn, Sandro Eckhardt, Walter Bodmer and the Nobel award winning, Harald zur Hausen.

An era of transition from being a pioneering convergence of Institute Directors to becoming an organisation focused on the real needs of cancer institutes began under the Presidencies of Professors Guy Storme, Thomas Tursz and Ulrik Ringborg, who had the foresight of an evaluative, multidisciplinary approach to cancer treatment and the internal organisation of cancer centres, which needed to be developed at supra-national level in order to guarantee basic rights for all European cancer patients to access high quality cancer care structures.

The following Presidents, further to confirming their commitment to the process of Accreditation and Designation, continued to reinforce the OECl's role in translational research, precision medicine and molecular approach to cancer patient therapies, as well as in financial aspects related to cancer treatment.

I leave it up to the OECl members to assess my Presidential mandate, which I hope will not only be remembered as the first Presidency assigned to a woman and the longest one, but also at least for my determination in following democratic principles and in making sure that the OECl would not fall prey to pathways that could deviate from our core mission, assigned to us and expected from our patients: quality and equity in cancer care.

Unfortunately, we did not manage to reach the 100 member target for the OECl, but we reached the finish line with 88 OECl members on board, a result of our hard earned efforts and increased visibility and attractiveness of the OECl and its Accreditation and Designation Programme, now ISQua recognized.

I would also like to remind our members that the OECl has not forgotten its historical heritage, left behind by our predecessors and continues today with its commitment to also deeply involve the cancer centres from Eastern Europe in the OECl projects and activities, and especially to encourage their interest and participation in our accreditation system. The realisation of a Russian language version of our OECl website should help to bring our Russian colleagues on board and is a unique example amongst international cancer organisations.



Dialogue has remained open and the OECl is exemplary in its commitment to fostering détente in the pursuit of relationships - be they scientific, political, commercial or social interactions - between east and west: cancer illness has no borders and our duty is, and will always be, that of defending the rights of our patients. This was my commitment dictated by my role as the General Medical Director of the Institut Jules Bordet, but also in my role of clinician as a breast cancer medical oncologist, following on a daily basis real life situations and problems faced by our cancer patients and relatives. The creation of some new OECl Working Groups on Supportive and Palliative Care, as well as on Collaboration for Good Practices with Patients in partnership with the European Cancer Patient Coalition has widened the scope of our new challenges and prospects

I would like to conclude with some words from Federico Mayor, Director-General of UNESCO from 1987 until 1999, who reminds us how much our boundaries, whatever they may be, need a constant window of dialogue, knowledge and openness towards others:

“Keeping closed within ourselves we risk getting lost ourselves in the undisputed wisdom of our qualifications, our establishments, and our cultural heritage”.



Tribute to Umberto Veronesi

Gordon McVie *e-cancer*

Giovanni Apolone *Fondazione IRCCS- Istituto Nazionale dei Tumori di Milano*

Professor Umberto Veronesi was a world famous cancer surgeon whose exceptional contribution to current cancer care is beyond compare. His innovations and extraordinary skill to bring people to work together was typical of the man, and one of his many new ideas was the foundation of the Organisation of European Cancer Institutes (OEI), celebrating its 40th anniversary this year.

Throughout his extraordinary career, Veronesi's mantra was to define the minimal effective treatment which improves the quality of life of patients, with his groundbreaking studies leading to a world-wide acceptance of conservative surgery in all forms of cancer.

Over his 60-plus year career, most of them working at National Cancer Institute of Milano, the comprehensive cancer centre where he started his career in 1954 and obtained the most important research results during his life, he was the first to dare trial the conservative management of breast cancer instead of mutilating mastectomy. During this 40-year career period at National Cancer Institute of Milano, thanks to his courage and subsequent confirmation of his trial results, millions of women have been cured without losing a breast even if he was widely criticised by surgical colleagues and accused of unethical treatments. Veronesi operated on over 30,000 women and always followed his personal code of treating the whole patient, not just the disease. He also pioneered the sentinel node biopsy procedure to avoid lymph node dissection, and intraoperative radiotherapy in breast cancer. Veronesi fostered the concepts of adjuvant chemotherapy and chemoprevention, continually striving not to take anything for granted and driven by curiosity to find better ways of doing things. His work in breast cancer included studies on therapeutic prevention, including retinoid fenretinide and tamoxifen. He was also involved in parallel studies in melanoma, sparing thousands of patients from the complications of unnecessary lymph removal and need to undergo large disfiguring skin grafts.

Veronesi is widely acknowledged by his peers as a visionary who led a humanitarian crusade to improve the lot of mankind and maintain the dignity of cancer sufferers. In this quest he initiated the Science for Peace, and the Future of Science global conventions, founded the European School of Oncology, EUSOMA, the OEI and Europa Donna.

He also founded the European Institute of Oncology (IEO), a comprehensive cancer centre with a strong research component based in Milan, Italy. The IEO has become a highly respected institution, treating around 40,000 new cancer patients each year at its height of success. Veronesi's foundation, the Fondazione Umberto Veronesi, promotes the wider appreciation of ethical values intrinsic to science. As Veronesi himself said "The raison d'être of science is not research per se, but its benefits to humans and progress,".

Between April 2000 and June 2001 Veronesi was Minister of Health in the Italian government and was Senator of the sixteenth Italian Parliament from April 2008 to February 2011. He was extremely popular with the public, making the Panorama magazine list of the 10 most popular people in the country many times. He was responsible for many improvements to the healthcare system in Italy during his political career, including the introduction of compulsory continuing medical education and the abolition of the system where patients had to pay to be treated by a doctor.

Further to his belief that knowledge should be free, in 2007 Professor Veronesi co-founded ecancer.org, with Professor Gordon McVie. ecancer.org is a pioneering online open access journal and medical education platform, and is the Official Journal of the OEI. The goal of the organisation both then and now is to speed up free cancer communication globally and improve patient care via better

professional education. ecancer.org continues to be an embodiment of Veronesi's vision of an independent cancer journal which is free to read and is mainly funded by charitable grants and sponsorship.

During his career he also served as the head of organisations including the International Society of Cancer Chemoprevention, the Union for International Cancer Control (UICC), the Committee of Cancer Experts of the European Union, the Federation of European Cancer Societies (FECS) and was EORTC President from 1985 to 1988. Renowned for the rigour of the science underpinning his surgery, Veronesi authored more than 790 papers on Clinical and Experimental Oncology and 12 oncological treatises.

With the death of Umberto Veronesi the world has lost a true visionary. He will be sorely missed by everyone who had the privilege to know and work with him, and millions of cancer patients around the world will continue to benefit from his life's work for many years to come.



Prof. Umberto Veronesi at First Edition of the OEI Oncology Days Genoa, 2008



Vision 2030 for the optimal approach to cancer research and care in Europe: a mission or a Network of Networks?

Thierry Philip Institut Curie



A mission-oriented approach to cancer care in Europe was proposed by Julio Celis and Dainius Pavalkis early 2018. The major proposed objective is to achieve a long-term survival of 3 out of 4 cancer patients by 2030.

This goal is laudable and ambitious. Given the importance of the task, it may only be reached if the overall cancer community will be able to better apply the existing “instruments” to provide high quality cancer care, offering a higher percentage of cancer patients the possibility to benefit of the best available treatments. It should also be complemented by developing a capacity of early intervention to avoid the disease before it actually reveals itself. Therefore, if we want to reach the survival goal above-cited and prevent a disastrous disease outbreak in the future, important issues should first be debated at a European level:

- How to facilitate interactions among and improve quality within the most performant cancer centres?
- How to support the access to innovation and the growth of centres that have not reached yet a level enabling them to offer the best available treatments for a wide range of cancer patients?

The cancer community must share a fundamental responsibility to act collectively and in today's era of World Wide Web, it is time to think out of the box and consider the possibility of establishing a network of networks.

I. The Challenge

Cancer prevention is obviously the first and far most important challenge.

Early diagnosis and screening are thereby obviously the second major challenge to achieve long-term survival in Europe.

Fundamental research is a third (may still be one of the most important in a long-term vision) contribution to approach the 2030 challenge of cancer in Europe.

Translational research, to transfer research discoveries from bench to bed and vice versa is obviously a fourth major challenge to achieve the targeted long-term survival of 3 out of 4 cancer patients by 2030.

II. A network of networks forward-looking approach to define a mission-oriented approach to a virtual pan-European e-cancer Institute project.

A possibility, as briefly described below, is to set up coordination between currently existing networks that have the potential to evolve over time.

1. The main challenge is at the level of primary prevention, which could reduce the number of cancers by 30 to 40%. Virtual networks already exist, mainly **around Cancer Prevention Europe**, the European Network of Cancer Registries, the European Cancer Leagues and a certain number of other groups. It should be straightforward to create this first network, perhaps in collaboration with international Organizations such as IARC-WHO and UICC.

2. The European CanCer Organization (ECCO) which brings together both cancer specialists and patients, is entirely legitimate to establish a second network focused on the issues related to cancer care from screening to diagnosis (<https://www.ecco-org.eu>).

3. The third level is obviously fundamental research to nurture our knowledge. The EU-LIFE alliance, for instance, represents an interesting model in the spirit of an open approach. Starting with 13 of among the best European basic research centres, it aims to allow new members to join based on specific inclusion criteria in a progressive manner and to foster links with other groups.

4. Translational research represents one of the key objectives of both EU-LIFE and Cancer Core Europe. Together they could contribute to a fourth level on cancer translational research, including clinical research as well. However, new drug development is not sufficient to solve the issue of the fight against cancer by itself.

5. The topic of centralization of real-life data of patients treated for cancer is of great interest in terms of outcomes. A specific European network on this topic would be the last missing piece of the puzzle in order to create a Virtual European Cancer Institute. Given its links with the existing national networks, OEI in relation with the Cancer Core initiative is in a particularly strong position to contribute to the development of novel real-life approaches, raising the question of the price of innovative treatments.

All the above levels are needed and should positively interact and collaborate thanks to a solid though flexible and creative coordinating network. “The head” (the virtual European cancer institute) should be composed by a team of 20 to a maximum 40 officers acting as “conductors” and facilitating the creativity and expression of the individual networks with a bottom-up approach representing the overall community.

III. How select members of the networks will be a major issue

As far as translational research and clinical research are concerned, we need selecting the comprehensive cancer centres in a first phase (cancer centre or virtual cancer centres within a university hospital) and focus on their capacity to join a network for translational research.

This is one of the issues OEI/Cancer Core Europe and several European Joint Actions are currently addressing. Indeed, the European Networks on Rare Cancers (rare solid cancers of adults, paediatric tumours and rare haematological malignancies) have proved to play a major role to ensure the same high level of quality of care for all patients affected by these rare malignancies.

The whole cancer community, together with the representatives of our patients, effectively linked to all domains of research, should communicate effectively in order to discuss and design the way Europe should act to guarantee a sustainable future for cancer research and care.

A future built on an open, multidisciplinary, democratic and transparent approach including all the necessary talents.

Designation as a comprehensive cancer centre by OEI may be the first step to become part of a Network for translational research.

The building of a virtual European Cancer Institute based on coordinated networks should refer to unquestioned criteria using a solid and proven methodology operated by an independent arbitration body. Quality and meritocratic criteria are the foundation on which to build such an initiative.

OEI is enthusiastic to be part of such a vision to build together a real network, including all European citizens so as to increase duration and quality of life everywhere in our community.



End of term for two key OEI Board Members: a tribute to Marco Pierotti and Wim H. van Harten

Dominique de Valeriola
Institut Jules Bordet

On June 2018, the two longest serving OEI Board members, who also held OEI Presidential mandates, will end their term of office and leave the Board.

Dr. Marco Pierotti was elected to the OEI Board in June 2006 and served as President from June 2008 to June 2011. Dr. Pierotti began his Presidential duties during the OEI General Assembly held in Genoa on May 22nd 2008. Under his Presidency, the first Edition of the OEI Oncology Days and Scientific Conference was initiated.

Dr. Pierotti was the first Italian President of the OEI. His background as a molecular biologist prompted him to strongly support the vision of an OEI committed to translational research and in the setting-up of the OEI WG on Molecular Pathology. He also reinforced the link with EACR, of which he had been a previous President.

Thanks to his past experience in different national and international cancer Societies and Organisations, he supported the recognition of the value of OEI Accreditation and Designation Programme as one of the most important pillars of the OEI mission. Similarly, he was convinced of the central role of the patient as demonstrated by his firm support of the ECPC, to promote initiatives and create paradigms of valuable collaboration.

The OEI participation both in the EurocanPlatform Coordinated Action and in the Eurocancercoms Project also marked Marco Pierotti's very active and dynamic Presidency. His wish to bring people together and his openness to discussion yielded a steady increase in OEI membership, and in particular, Italian cancer centres.

Professor Wim H. van Harten was elected to the OEI Board in June 2005 and he served as President from June 2011 until June 2014.

Professor van Harten played an important role in bringing more methodology to the OEI projects, infusing OEI with professionalism and strengthening the A&D programme. The Benchmarking activities also started thanks to Wim van Harten, through a project coordinated by the OEI and supported by the EC Directorate-General for Health and Consumer Protection. Much effort was put into laying down the vital ground work towards a formal recognition of the OEI certification of CCCs as the necessary starting point for achieving European recognition of excellence in translational cancer research. The first revision of the A&D criteria was completed and the system was presented internationally at major association events, such as the AACI and the Asian Society of Clinical Oncology.

The First Edition of the European OEI Oncology Prize was also initiated under Professor van Harten's Presidency and awarded in Brussels during the 6th Edition of the OEI Oncology Days, to Professor Ulrich Ringborg.

The OEI Board would like to extend its appreciation and thanks to both Marco and Wim for their outstanding service, dedication, approachability and huge contribution to the OEI and its growth.



Innovative Partnership for Action Against Cancer (iPAAC) at the start line

Tit Albreht, Karmen Hribar and Tina Lipuscek
National Institute of Public Health, Slovenia

Cancer continues to present one of the key public health challenges in the European Union. Over the last 8 years, we have seen an intensification of the activities at the level of the European Union in order to tackle cancer from different aspects. Still, a number of important outstanding issues in cancer control remain unaddressed. The Innovative Partnership for Action Against Cancer (iPAAC), which has been selected for funding under the Third Health Programme 2014 – 2020, aims to build upon the outcomes of previous EPAAC and CANCON Joint Actions.

The general objective of the iPAAC Joint Action (JA) is to develop innovative approaches to advances in cancer control. The innovation that will be covered within the JA consists of further development of cancer prevention, comprehensive approaches to the use of genomics in cancer control, cancer information and registries, improvements and challenges in cancer care, mapping of innovative cancer treatments and governance of integrated cancer control, including a new analysis of National Cancer Control Plans. The key focus of the Joint Action will be on implementation, reflected in the key deliverable: the Roadmap on Implementation and Sustainability of Cancer Control Actions, which will support Member States in implementation of iPAAC and CANCON recommendations. The Roadmap will act as the central pillar of the JA, integrating the diverse topic areas, ensuring consideration of transversal issues for all topics and acting as the central comprehensive deliverable, integrating all the JA outputs. A variety of methods will be used to fulfil the general and specific objectives of the iPAAC JA including pilot studies, working groups, expert panels, literature review and surveys. This Joint Action aims to add value at the EU level by enhancing collaboration in the field of cancer with extensive exchange of good practices, successful implementation of different programmes and gradual reduction of the cancer burden in Europe and the world.

The iPAAC Joint Action has officially started on 1st April 2018 and it will last for three years. It includes 40 partners from 24 European countries and will be coordinated by the National Institute of Public Health Slovenia (NIJZ). More information about the iPAAC Joint Action can be obtained by visiting the official website (www.ipaac.eu) or by contacting the coordination team (ipaac@nijz.si).



Kick-off meeting
Joint Action iPAAC
April 17th 2018
Luxembourg

Joint Action on Rare Cancers and European Reference Networks

Paolo Casali and Annalisa Trama

Fondazione IRCCS- Istituto Nazionale dei Tumori di Milano

The Joint Action on Rare Cancers (JARC) is the first European Joint Action dedicated to rare cancers. This is important because so far there have been Joint Actions on rare diseases and on cancers but never on rare cancers. Thus, the JARC confirms that the EU is prioritising rare cancers per se. The JARC is a 3-year joint action (October 2016-October 2019).

The public health challenge posed by rare cancers combines both the typical problems of rare diseases (such as the limited professional expertise available in the community, or the difficulties in clinical research) and those of cancer, with the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathologic and biological assessment of the disease of the individual patient is key to survival and cure, as well as an expert clinical decision provided by a multidisciplinary team. To this end, proper referral of patients and effective clinical networking are crucial in rare cancers.

This is the main reason why JARC decided to shape its efforts, in essence, around the new European Reference Networks (ERNs). ERNs, three of which are specifically devoted to rare cancers, have been conceived by the EU Commission as a means to provide "highly specialised healthcare for rare or low-prevalence complex diseases". The formal activation of ERNs is a cornerstone in the EU cooperation on rare cancers, and the JARC will be instrumental to make them grow up the best way possible. In fact, JARC aims at optimising the process of creation of the ERNs, by providing them with operational solutions and professional guidance in the areas of quality of care, epidemiology, research and innovation, education and state of the art definition on prevention, diagnosis and treatment of rare cancers.

The 3 ERNs dedicated to rare cancers are:

1. the European Reference Network on adult cancers (solid tumours) - EURACAN;
2. the European Reference Network on haematological diseases (including rare haematological cancers) – EuroBloodNet
3. European Reference Network on paediatric cancer (haemato-oncology) - PaedCan

Generally speaking, the ERNs are virtual networks of centres of expertise and healthcare providers that are organised across borders. They create a clear governance structure for knowledge sharing and care coordination across the EU.

However, Member States remain primarily responsible for the organisation and delivery of their healthcare; national participation in ERNs is therefore voluntary. When a healthcare centre does not have the required level of expertise to be part of an ERN as a centre of expertise it can participate as an associated or collaborative centre. Thus, the ERNs will provide healthcare professionals with access to expertise that they may not be able to access in their country.

ERNs promote the sharing and mobility of expertise, rather than the movement of patients themselves across borders. Separately, the Directive on Patients' Rights in Cross-Border Healthcare allows patients to access healthcare services abroad and to be reimbursed by their home country at the level foreseen within the national "basket of benefits".

In this framework, what has the JARC done so far?

ERN implementation

Regarding the ERN implementation, the integration of the ERNs in the national health care system, the work-load associated and the limited funds currently available are a major concern.

In this regard, the JARC and the ERN EURACAN are promoting the establishment of national networks in each EU country. This means that the expert centres officially involved in the ERNs should become the hubs of national or regional networks to create networks of networks. This will ensure that the ERNs will make sense and will be efficient. The degree of belief in networking from health care system can be measured by the amount of resources they will dedicate to the ERN and the national networks. As healthcare systems differ across Europe, there is no 'one size fits all' approach to supporting ERN members and the JARC will closely watch what will happen.

Quality Service Standards for ERN

OEI is leading the JARC work package on quality standards for rare cancers network. A consensus meeting will be held on the 20th of June during the oncology days of the OEI in Poznań, Poland. These standards should contribute to make hospital and health system managers appreciate the value of ERNs, and the work of coordinators and members. On the other hand, these standards will help ERNs to convince this people that the ERNs are the instrument for raising the quality and equitability of care for rare cancers patients.

Education for rare cancers in the framework of the ERN

The JARC is collaborating with the European School of Oncology (ESO) and the European Society of Medical Oncology (ESMO) to develop educational events in collaboration with the ERN for professionals and patients.

Educational events on rare cancers in general:

"ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancers". (partnership among ESO, ESMO, RCE, EURACAN)

<http://www.esmo.org/Conferences/Past-Conferences/ESO-ESMO-RCE-Clinical-Update-on-Rare-Adult-Solid-Cancers-2016>

<http://www.esmo.org/Conferences/Past-Conferences/ESO-ESMO-RCE-Clinical-Update-on-Rare-Adult-Solid-Cancers-2017>

Dedicated post graduate course on specific rare cancers family

"Post-Graduate Course – Clinical Oncology: head and neck cancers". Milan, 2nd-9th February 2018 (partnership among the University of Milan, ESO, EURACAN)

"Post-Graduate Course – Clinical Oncology: sarcomas". Milan, 22nd-26th January 2018 (partnership among the University of Milan, ESO, EURACAN)

Guidelines for rare cancers in the framework of the ERN

After an extensive mapping exercise on all clinical practice guidelines available for rare cancers, the JARC worked with the ERN EURACAN to shape a new model for clinical guidelines development, which involve ESMO and ERN experts. This model was successfully applied to the sarcoma family of rare cancers. Thus, the first edition of the "Gastrointestinal stromal tumours: ESMO-EURACAN Clinical Practice Guidelines for diagnosis, treatment and follow-up" and "Soft tissue and visceral sarcomas: ESMO-EURACAN Clinical Practice Guidelines for diagnosis, treatment and follow-up" has been finalised and is currently in press. A draft of the bone sarcoma ESMO-EURACAN Clinical Practice Guidelines has been developed and is currently under evaluation in partnership with PaedCan, which has thus been involved, given the median age of some bone sarcomas.

ERN registry and population based cancer registry

Registry data is of growing interest in healthcare as a source of real-world information on all diseases. As ERNs have the capacity to generate patient data for rare cancers on an unprecedented scale, it will be important to define how data will be collected and used. The JARC is working to address issues of quality, interoperability and usability of this data. In addition, the JARC is working with the European

Network of Cancer Registry and the Joint Research Centre on a proposal for positioning the population-based cancer registries in the framework of ERN evaluation and research on rare cancers

Promoting the discussion with regulatory authorities

The JARC is discussing with the European Medical Agency (EMA) drug licensing in rare cancers. A first meeting with the EMA was held on the 16th of April 2018, including chordoma and ACC of the head and neck as models of rare cancers.

To conclude, there are many challenges ahead of ERN and JARC however; ERNs did not appear from a vacuum. They were built on a robust policy and legal framework. Now that they are established, several Joint Actions including the JARC are available to support their work and make them grow up the best way possible.

Our institution in Milan, Istituto Nazionale Tumori, with a long tradition on several rare cancers, has the privilege to serve as the coordinator of the JARC. We will try to meet the expectations as much as we can, counting on the exceptional professional skills, the engagement and the passion we have been able to find in all the partners of JARC. Most important, patients will be with us, across all work packages, driving our efforts along the needs of the only end users of all what we can do, in care and research as well.



EURACAN European rare adult solid cancer network state of the art

Jean-Yves Blay
Institut Léon Bérard

EURACAN is a European Reference Network on **rare adult solid cancers** including 66 centres from 17 European countries. It is coordinated by the French Comprehensive Cancer Centre Léon Bérard in Lyon, France.

It is dedicated to the improvement of diagnosis, treatment management, knowledge, research and communication on all adult solid rare cancers for patients, families, physicians and all stakeholders. Within the network, rare adult solid cancers are grouped in ten domains corresponding to the RARECARE list of rare cancers based on the ICD-O: sarcoma, Gynaecological, Urological, Neuroendocrine, Digestive, Endocrine, Head and Neck, Thoracic, Skin and Ocular melanoma, brain and central nervous system.

During the first implementation year the 10 Domains have started the homogenisation of Clinical Practice Guidelines to **spread and align best practices**. In parallel, the first **training and education activities** have been organised within the domains of Sarcoma and Head and Neck cancers in association with other European organisations already active and acknowledged in the field. This activity was undertaken by the Transversal Task Force on Training and Education activities, led jointly by ESO and Istituto Nazionale dei Tumori di Milano.

Patients across the EU can have access to the best expertise available on diagnosis and treatments through the **Clinical Patient Management System (CPMS)**, a web-based clinical software application provided by the European Commission. The CPMS allows healthcare providers from all over the EU to organise **virtual consultations** and share experience across national borders.

Communication tools dedicated to patients and physicians have been developed to **promote EURACAN initiative**: a public website translated into ten Member State languages, a Facebook page, a Twitter account and leaflets which will be disseminated by the whole network and describe the ten rare cancer domains and EURACAN activities.

To stimulate research on RAC, EURACAN is involved in The Rare Disease European Joint Programme and will actively contribute to the creation of a research and innovation pipeline "from bench to bedside". Thirty EURACAN members joined The EORTC SPECTA clinical research infrastructure and 6 applications have been submitted to the Fourth Joint Transnational Call 2017 on Translational Research on Rare Cancers TRANSCAN -2.



EURACAN
European network for
Rare adult solid Cancer

OEI and ECCO Summit 2018

Claudio Lombardo
Organisation of European
Cancer Institutes (OEI)

As cancer care has recently registered a paradigm shift from a disease-focused to a patient-centred management, multi-disciplinarity emerges as a paramount necessity for a better coordination of the pipeline connecting health professionals to cancer patients.

Within this framework, from the 7th - 9th September, Vienna will host the ECCO 2018 Cancer Summit, bringing together major global players of the cancer care community on a unique multidisciplinary forum.

ECCO's history evolves entirely around the concept of multi-disciplinarity. With its 23 member societies, this cohesive platform was created so as to uphold patient-centricity, whilst driving improvement in cancer care across Europe. These are all goals ECCO shares with the OEI, a network of Cancer Centres designed to promote efficient partnership across Europe in order to create a global vision of cancer problems by integrating research and education with diagnosis, prevention and care.

The above clearly proves the reason why OEI is interested in the ECCO Summit Programme, its dissemination and implementation to all possible recipients.

The Summit will open with a Session on "Outcomes Research", a branch of public health research which deals with the outcomes of the health care structure and processes on the well-being of patients. "Cancer outcomes research" is also one of the OEI Working Groups, therefore data collection, storing and evaluation are common pillars OEI shares with ECCO.

Further on, the Summit will address inefficiency in cancer care, whilst exploring the role of multi-disciplinarity in this regard. Cancer care quality, the role of multi-disciplinarity and the expectations of patients play a central role in the OEI politics and actions too. A specific Working Group on Collaboration for Good Practices with Patients cooperates with the European Cancer Patients Coalition (ECPC) and the OEI interest in this Session is maximal.

All cancer centres and institutes share a common goal: quality in cancer care, but how can we define what it consists of and acquire a reliable measure of the level of quality of cancer care being delivered? The OEI answers these three fundamental questions, examined during the "Quality in cancer care: how to demand it, measure it and implement it" Session, with its A&D Programme, designed for cancer centres that want to measure their performances and carry out a self-assessment to be further evaluated by a peer review approach.

Scientific advances such as immunotherapy, targeted therapy and precision medicine recently improved the cancer care scenario. Nonetheless, countries around the world continue to struggle with the costs to be sustained for innovative cancer therapy. The ECCO Summit will face this topic in the debate Session "Putting a price on cancer medicines: the challenges and prospective solutions".

The OEI also tackled this matter by setting up a specific Working Group on Cancer Economics to examine ways to reduce the cost of drugs to be used in therapy for low-income countries as it should be compared to the cost of living, the purchasing power or pro-capita income of each country.

OEI wishes a positive outcome to the Summit and invites its Members to contribute with their presence to a successful Edition of ECCO 2018.

Learn more about the ECCO Summit 2018 at:
<https://www.ecco-org.eu/ECCO2018Summit>

ECCO Board of Directors
Villa Verganti Veronesi
Inveruno, May 4th 2018



Why should you be at the 2018 World Cancer Congress in Kuala Lumpur

Jessica Mathieu
Union for International
Cancer Control- UICC

This year, the Union for International Cancer Control (UICC) and its partners are bringing the World Cancer Congress to Kuala Lumpur, together with 3,500 delegates from more than 140 countries.

Here are a few reasons why you should join us from the 30th of September to the 4th of October 2018 and make the most of a week of outstanding education on cancer and other non-communicable diseases control:

1. It is the only Cancer Congress that addresses the full depth and breadth of cancer control - from prevention and early diagnosis to treatment and palliative care. Through circa 150 interactive sessions, the programme is brimming with the latest evidence-based methods in cancer implementation science.

Pertinent topics that prevail on global and national health agendas such as national cancer control planning, obesity, tobacco control, alcohol, HPV vaccination and economics of cancer care feature prominently in this year's programme.

2. We are privileged that leading oncologists, academics, researchers, policy-makers, health carers, fundraisers and corporate leaders give their time and energy to the Congress.

Each session, plenary, big debate, discussion café or capacity building scheme involves experts in their field, delivering their perspectives to audiences keen to learn what is working in other parts of the world.

There are many accounts of past participants who took advantage of the Congress to further their personal development too. The story of a paediatrician from South East Asia, who raised US\$100,000 for paediatric cancer after putting into practice what he learnt at one of our Master Courses, is a great example of how a researcher stepped outside his comfort zone to succeed beyond his expectations.

3. You will also find a lot of networking opportunities and meet incredible people who will inspire and empower you to do a better job today than tomorrow.

View the full programme and register on www.worldcancercongress.org

We are looking forward to seeing you in Kuala Lumpur!



Patient-centred Quality Standards for Cancer Networks

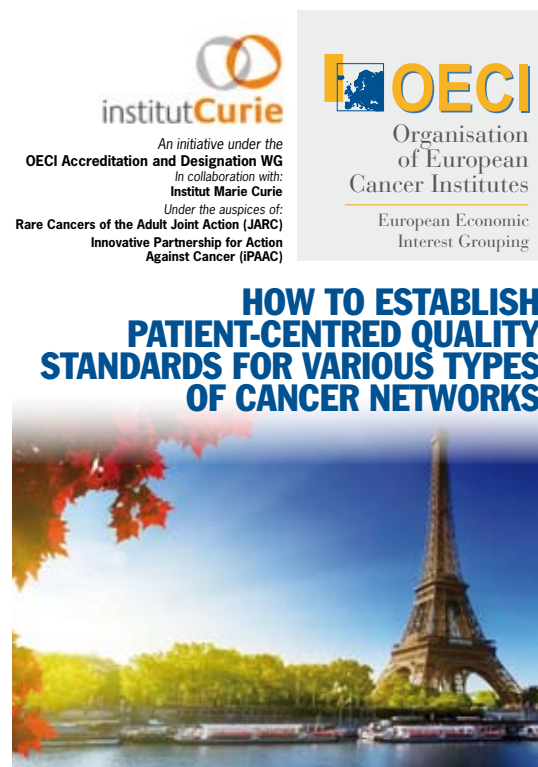
Simon Oberst
Cambridge Cancer Centre
Wim H. van Harten
Rijnstate Hospital

Throughout Europe the debate about organising optimal cancer care pathways is entering a new stage. Variations in specialist care provision, volume-outcome relationships, and differences in survival rates fuel this discussion, although most cancer patients in Europe are still being treated in a general hospital setting. In several European countries clinical audit systems are starting to generate more evidence on how to organise optimal cancer service provision. Government agencies and professional societies are actively defining quality criteria, and, increasingly, minimum volume numbers. Comprehensiveness is not only used to define close interaction between clinical care and translational research (as in Comprehensive Cancer Centre) but also as holistic and “all encompassing” (as in Comprehensive Cancer Network).

Increasingly, cancer care and research are being organised on a network basis, but these networks can take many and various forms in different countries in Europe. Some are top-down creations; others are organised from the bottom up. Based on our experience of setting and accrediting quality standards in Cancer Centres (both Clinical and Comprehensive), OECI wants to take a lead in setting and accrediting standards in Comprehensive Cancer Care Networks, to use the CANCON definition. OECI has already made great strides in defining quality standards for networks of rare cancers (as part of the Joint Action on Rare Cancers) which are often on a national, or international scale. Now we want to define the systemic and patient-centred standards for networks of more common cancers. We are particularly concerned to adhere to the tripartite model of care, research and education within networks.

To this end, OECI hosted a consensus meeting on Patient-Centred Quality Standards in Cancer Networks at the Institut Curie in Paris on 19th April 2018. We heard evidence from the sub-regional network in Rhône-Alpes in France, from South Moravia in the Czech Republic, and of developments on a national level in Denmark and the UK.

There is clear evidence that standards on governance, on infrastructure, on clinical guidelines, on continuity of care, on multi-disciplinarity and on data integrity, would be beneficial to improve patient outcomes and experience. OECI will be working over the next few months to take these ideas to the next level of detail, and to design pilot tests of quality standards for national, regional and sub-regional use. OECI will also be collaborating with the iPAAC and INTENT EU actions as they apply to defining networks and standards, and continuing our leadership of the JARC workpackage on quality standards for rare cancer networks.



Registration for the 2018 training for OECI auditors and audit chairs is now open

Harriet Blaauwgeers
Netherlands Comprehensive
Cancer Organisation, IKNL

Performing a peer review visit as an OECI auditor is a learning experience in your own professional life in the fight against cancer in your own Centre, as well as a crucial part of ensuring quality improvement in the applicant Cancer Centre.

You get the chance to examine all aspects of the Cancer Centre, how it is organised at the management level as well as at the clinical and laboratory levels for all disciplines: nurses, physicians, researchers, pathologists, management etc.

When and where?

Date: The training will take place on 20th and 21st November 2018 in Inveruno in the beautiful surroundings of the Villa Verganti Veronesi. It is organised by the OECI A&D Group, the OECI Liaison Office and Kerteza. At the end of the training the participants will receive a certificate of attendance.

Who are we looking for?

There is a special need for Directors who have the ability to act as chair of a team to strengthen our pool, as well as nurses and senior researchers (for instance Group Leaders or Principal Investigators in Trials). The maximum number of training participants is 16 people. A selection will be done on the basis of background, experiences and current positions of the applicants.

To qualify, an auditor needs to be employed by a cancer centre, and actively involved in cancer care, research, education, quality control or management. We need people who have the commitment from their management to perform an OECI audit on average 2 times per year and during the working time.

The training includes:

- Introduction in quality management and auditing;
- Introduction of the OECI quality standards, procedures and tools;
- Roles and responsibilities of auditors and chair of an audit team, as well as the OECI coordinator;
- Theoretical background and practical exercises on preparation of an audit, teamwork as an audit team;
- Role plays in performing an OECI audit.

The training is free of charge and it includes accommodation and travelling costs.

Learn more about the profile of a chair of an audit team and auditors at:

<http://www.oeci.eu/Accreditation>

The Training Programme will be soon advertised on the Accreditation website and disseminated at the OECI 2018 Oncology Days in Poznań, Poland. The interested applicants may send a demonstration of interest to accreditation@oeci.eu

For further information you may also contact:

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h.blaauwgeers@iknl.nl
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**The A&D training's site,
Villa Verganti Veronesi, Inveruno**



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