

News flashes

- e-learning project CRC
- INSPIRE – nipple sparing mastectomy
- International Watch & Wait Database IWWD

e-learning CRC on its way

Thankfully, funds are promised to develop the e-learning project. Part of EURECCA's key activities is reaching out to patients and health care professionals with standards of high quality cancer care. Therefore, in the near future, we will start with the design of a smart looking web-based educational platform. Freely and easily accessible, state of the art medical information presented in short

modules and drafted under auspices of the Education and Training Committee of the European Society of Surgical Oncology (ESSO), the patient advocates: Europacolon, and many more. Because we started this project with the colorectal group, the prototype colorectal cancer will be produced as the first. The oesophageal-gastric cancer group, have also expressed their interest to develop an e-learning for oesophageal an gastric

cancer patients. Our EURECCA e-learning will be innovative, because of its multidisciplinary landscape. Moreover, in partnership with Europacolon, a truly patient-centered e-learning will be designed with option grids and decision aids, patient experiences, all to promote shared decision making in colorectal cancer care. Different layers of information for medical professionals and patients will be created. For more information, please contact eurecca@lumc.nl

INSPIRE

INTERNATIONAL NIPPLE SPARING MASTECTOMY REGISTRY

INSPIRE, short for, International nipple sparing mastectomy registry, is a new project, being designed at this moment. The Case Record Files in PROMISE, our highly secure patient data server, are almost ready to be tested with the first pilot patients. The database will be opened for patients undergoing nipple sparing mastectomy in combination with immediate reconstruction for breast cancer or DCIS and/or risk reduction. Conventional mastectomy

routinely removes the nipple areola complex. A scar without a nipple leaves a poor cosmetic result. In the last decade, several studies have shown that NAC involvement is not as high as it was thought from historical evidence and more knowledge about the NAC anatomy and the terminal ductal lobular unit in the nipple has spread its practice. Nipple sparing techniques with immediate breast reconstruction may improve the patient's satisfaction and recover the body image; this may

result into psychological benefits for the patients facilitating the recovery process of the breast cancer diagnosis. EURECCA Breast group is working with the principal investigators Professor Isabel Rubio, Spain, and Professor Riccardo Audisio, UK. After a period of extensive testing, we expect to go live in the beginning of 2016!



Watchful waiting in rectal cancer



The international prospective watch & wait database for rectal cancer patients with clinical response to induction therapies is growing steadily. Patient data registration was opened in April 2015 with three pilot centers testing the set, opening in May for the first batch of centers. The number of participating hospitals who received an

account is 42 centers coming from 14 countries globally. To participate in this project, centers need to endorse the call of agreement as described on the website www.iwwd.org. Moreover, interested centers need to provide contact information and a logo for patients to reach them. Currently 405 patients are prospectively followed in the database. Angelita Habr-Gama, Geerard Beets, Nuno Figueiredo, and Cornelis van de Velde, wrote an editorial in the European Journal of Surgical

Oncology which is currently online available, explaining the relevance of the project in light of organ preservation. Nuno Figueiredo, working at the Champalimaud center of the Unknown in Lisbon has presented the first descriptives of the patients in the IWWD set, his presentation can be found on the website. A large group of international experts met in November at the FICARE Meeting in Sao Paulo, where organ preservation was high on the agenda. We look forward to present more of the IWWD in the future.

“Paradigm shift a head in rectal cancer treatment is online in the European Journal of Surgical Oncology.

PMID:26493223”



EURECCA- UGI- exploring the alternatives

Watchful waiting of complete responders is very promising in selected patients. Oncological safety, failures and functional outcome are of utmost importance to unravel of watchful waiting strategies. Treatment of oesophageal cancer has become multimodal in time and pathological complete responders after oesophagectomy are reported as high as 40%. The question rises whether watchful waiting could be an alternative treatment for resectable responders to induction chemoradiation in oesophageal cancer

avoiding high postoperative morbidity and mortality. For oesophageal cancer restaging after induction treatment is not as robust as it might be in rectal cancer patients. Fibrosis at restaging remains a huge problem to detect regrowth's. Moreover surveillance programs are not existent.

Watchful waiting is the more proactive approach of (definitive) chemoradiation omitting surgery only if is harming the patient and offering salvage surgery if detecting a regrowth at frequent follow ups. Because resectability is not always possible due to patient factors such as comorbidities and age or

tumour factors as locally advanced disease and distant metastatic site; some patients are already treated with definitive or induction chemoradiation for (un)resectable oesophageal cancer. In a recent series overall 3-year and 5-year survival are reported as 44% and 31% (Hihara et al). We are interested to prospectively follow these patients up to explore watchful waiting in oesophageal cancer. If you are interested to this challenge, please contact EURECCA's office in Leiden. Bill Allum is our chair of the Upper GI group.

Lars Pålman in memoriam

Following some years of fight against a malignant disease, Professor Lars Pålman passed away on Saturday November 21, 2015, at the age of 69. Lars Pålman had a never-ending interest in every aspect of coloproctology and his contributions to improve the quality of cancer care for all patients with colorectal cancer have given echo world-wide. He initiated the Swedish rectal cancer trial and was joint coordinator of adjuvant and current RAPIDO-trial in the Netherlands. Lars Pålman was the founder of and driving

force behind the Swedish Colorectal Cancer Register - an effort of great importance not only for patients in his native country. His most profound impact was probably pioneering pre-operative radiotherapy, in particular short-course irradiation, for rectal cancer. His work in this field has been invaluable in the struggle to reduce local recurrences and improve survival for patients. As long time board member of ESSO and our President between 2002-2004. Lars was devoted to promote ESSO and its mission. Also he was on the basis of EURECCA

Colorectal as a coordinator of the European Audits. And most of all, Lars was a dear friend and an inspiration for younger surgeons. Lars was a passionate stamp collector and nobody will forget his exposé of anti-tobacco stamps sending a sharp and clear message to conclude many lectures. Lars was never late to tell a joke and the room was filled with smiles and laughter. Lars Pålman has left us all too early but his contributions and memory will stay.

Cornelis

The role of resection of the primary tumour for asymptomatic incurable metastatic colorectal cancer

Approximately 20-25% of all newly diagnosed patients with colorectal cancer have metastatic disease at diagnosis. Still the majority of these patients cannot be curatively treated. Surgical resection of the primary tumour is often performed in case of obstruction or perforation, or to prevent primary tumour complications. However, in patients with asymptomatic incurable disease, the role of surgery of the primary tumour is still debated. Several retrospective studies suggested a benefit of surgery of the primary tumour, but no

solid conclusions can be drawn based on these studies because bias due to confounding by indication cannot be excluded. Currently, the role of resection of the primary tumour in patients with few or no symptoms of incurable metastatic colorectal cancer is investigated in the CAIRO4 study. However, this study is still enrolling patients and the results should be awaited. Another option to investigate the role of surgery of the primary tumour in patients with incurable metastatic colorectal cancer who did not undergo emergency

surgery of the primary tumour is to use comparative effectiveness research. The aim of the current EURECCA international comparison is to study the association between treatment strategies and survival between Norway (with a high proportion of surgery of the primary tumour) and the Netherlands (with a low proportion of surgery of the primary tumour) in patients with incurable metastatic colorectal cancer who did not undergo emergency surgery of the primary tumour. First analyses will be done in December 2015.

By Anne Breugom, PhD





The patients voice of
digestive cancers in the
EURECCA Network

About ProMISe

ProMISe (Project Manager Internet Server) is a web-based relational database management system for the design, maintenance and use of (clinical) data management. This ProMISe system provides in custom made databases for scientific medical research as well as an application for on-line data entry, quality checks and reporting. It also provides a tool for data retrieval to facilitate statistical analysis. ProMISe can be applied for single- as well as for multi-center studies. ProMISe is developed within the Leiden

University Medical Center (LUMC). Prof Ronald Brand is head of the Section Advanced Data Management (ADM), which is responsible for the development and maintenance of new ProMISe-projects. New ProMISe-databases are developed in consultation with the researcher(s) concerned, keeping in mind the scientific goal of the new database. ADM works in close collaboration with the statistical staff of the department of Biostatistics & BioInformatics of which it is an integral part. ADM is NEN7510 certified and ProMISe meets the

requirements for data-safety and privacy set by international law. Due to this certification the ProMISe system facilitates the availability, integrity and confidentiality of your data. ProMISe facilitates you to store, exchange and retrieve data according to the security conditions demanded by GCP.

The two prospective databases of EURECCA IWWD and INSPIRE are designed in ProMISe.

EURECCA Breast – How about axillary treatment in EUROPE

During the EURECCA Board meeting at the European Cancer Congress 2015 in Vienna. Marjut Leidenius proposed to study the axillary treatment strategies in Europe. After the publication of the Z0011 of the team of Giuliano, and the AMAROS trial, axillary treatment changed and national recommendations of treatment of the axilla in patients with breast cancer were renewed. Because, some countries might differ in their outlooks. We are interested to find out what are the recommendations and clinical practices of

patients with isolated tumour cells in the sentinel node, micro-metastasis and macro-metastasis. To study this in Europe, the questionnaire on treatment of patients with breast cancer with macrometastasis that was issued by the Dutch group of the Catharina Hospital Eindhoven among Dutch Breast surgeons on their practice of axillary treatment is translated to English and will be disseminated among the representatives of surgical oncologists in Europe. We invite all countries in Europe to join this

upcoming call of study to unravel recommendations in axillary treatment in breast cancer. Future research would investigate different alternative treatments in relation to oncological outcome, such as disease-free survival and overall survival and guideline adherence. Principal investigators of this project are Marjut Leidenius, Sabrina Maaskant and Gard Nieuwenhuijzen.

Gusje Vugts is the PhD on the project.



EURECCA Pancreatic cancer

The EURECCA-pancreas group is currently collecting data of 2012 and 2013 for a first international comparison. Of the 36 pancreas registries or audits 16 has responded, and 11 has participated in the definition of the common data set. Eleven complete lists of items were received from the collaborators; Austria, Belgium, Bulgaria, Denmark, Germany, The Netherlands, Slovenia, Spain, Sweden, Ukraine and the United Kingdom. The number of data items in the datasets varied between 16 and 285. A total of 25 items was

marked present in seven out of eleven datasets. The data of 2012-2013, are collected to study treatment patterns of these common data items among the European countries as was agreed upon in the call of agreement. Capturing clinical relevant international benchmarks is not challenged before in pancreatic cancer and would provide tools for feedback and improvement of health care infrastructures. Collaboration is key to obtain robust population-based data and will improve our knowledge of treatment of pancreatic

cancer care in Europe, more than results from clinical trials or from expert centers only. International comparisons are the unmatched measure to effectively benefit patients with pancreatic cancer. Please, join in this study call of EURECCA Pancreatic cancer.

Babs Sibinga Mulder is the PhD on pancreatic cancer.

EURECCA publications 2013-2015

Beets GL, Figueiredo NL, Habr-Gama A, van de Velde CJ. A new paradigm for rectal cancer: Organ preservation: Introducing the International Watch & Wait Database (IWWD). **Eur J Surg Oncol.** 2015 Oct 19. pii: S0748-7983(15)00774-X.
van de Velde CJ, Boelens PG, Borras JM, Coebergh JW, Cervantes A, Blomqvist L, Beets-Tan RG, van den Broek CB, Brown G, Van Cutsem E, Espin E, Haustermans K, Glimelius B, Iversen LH, van Krieken JH, Marijnen CA, Henning G, Gore-Booth J, Meldolesi E, Mroczkowski P, Nagtegaal I, Naredi P, Ortiz H, Pahlman L, Quirke P, Rödel C, Roth A, Rutten H, Schmoll HJ, Smith JJ, Tanis PJ, Taylor C, Wibe A, Wiggers T, Gambacorta MA, Aristei C, Valentini V. EURECCA colorectal: Multidisciplinary management: European consensus conference colon & rectum. **Eur J Cancer.** 2014 Jan;50(1):1.e1-1.e34.
van de Velde CJ, Boelens PG, et

al. Experts Reviews of the Multidisciplinary Consensus Conference Colon and Rectal Cancer 2012. Science, opinions and experiences from the experts of Surgery. **Eur J Surg Oncol.** 2014 Apr;40(4):454-68.
Valentini V, Glimelius B, Haustermans K, Marijnen CA, Rödel C, Gambacorta MA, Boelens PG, Aristei C, van de Velde CJ. EURECCA consensus conference highlights about rectal cancer clinical management: The radiation oncologist's expert review. **Radiother Oncol.** 2014 Jan;110(1):195-8.
Tudyka V, Blomqvist L, Beets-Tan RG, Boelens PG, Valentini V, van de Velde CJ, Dieguez A, Brown G. EURECCA consensus conference highlights about colon & rectal cancer multidisciplinary management: The radiology experts review. **Eur J Surg Oncol.** 2014 Apr;40(4):469-75.
Quirke P, West NP, Nagtegaal ID. EURECCA consensus conference highlights about colorectal cancer clinical

management: the pathologists expert review. **Virchows Arch.** 2014 Feb;464(2):129-34.

Breugom AJ, Boelens PG, van den Broek CB, et al. Quality assurance in the treatment of colorectal cancer. **Ann Oncol.** 2014 Aug;25(8):1485-92.
Boelens PG, Taylor C, Henning G, et al. Involving patients in a multidisciplinary European consensus process and in the development of a 'Patient friendly summary of the consensus document for colon and rectal cancer care'. **Patient.** 2014;7(3):261-70.

Quality assurance in surgical oncology. The EURECCA-platform. Editorial. Boelens PG, Audisio RA, van de Velde CJH. **Eur J Surg Oncol.** 2014 Nov;40(11):1387-90.

CBM van den Broek Differences in preoperative treatment for rectal cancer. Norway, Sweden Denmark, Belgium and the Netherlands. **EJSO** 2014 2014 Dec;40(12):1789-96.

Messenger M, de Steur WO, van Sandick JW, Reynolds J, Pera M, Mariette C, Hardwick RH, Bastiaannet E, Boelens PG, van deVelde CJ, Allum WH; EURECCA Upper GI Group. Variations among 5 European countries for curative treatment of resectable oesophageal and gastric cancer: A survey from the EURECCA Upper GI Group (European REgistration of Cancer CARE). **Eur J Surg Oncol.** 2015 Sep 30. S0748-7983(15)00792-1.

WO de Steur; D Henneman; W H Allum; J L Dikken; J W van Sandick; J Reynolds; C Mariette; L Jensen; J Johansson; P Kolodziejczyk; C. van de Velde. Common data items in seven European oesophagogastric cancer surgery registries: Towards a European Upper GI Cancer Audit (EURECCA Upper GI) **Eur J Surg Oncol.** 2014 Mar;40(3):325-9.

Kiderlen M, Ponti A, Tomatis M, Boelens PG, Bastiaannet E, Wilson R, van de Velde CJ, Audisio RA; eusomaDB Working Group. Variations in compliance to quality indicators by age for 41,871 breast cancer patients across Europe: A European Society of Breast Cancer Specialists database analysis **Eur J Cancer.** 2015 Jul;51(10):1221-30.

Kiderlen M, Walsh PM, Bastiaannet E, Kelly MB, Audisio RA, Boelens PG, Brown C, Dekkers OM, de Craen AJ, van de Velde CJ, Liefers GJ. Treatment strategies and survival of older breast cancer patients - an international comparison between the Netherlands and Ireland. **PLoS One.** 2015 Feb 3;10(2):e0118074.



E-MAIL:
eurecca@lumc.nl

Support EURECCA

EURECCA is a non-profit foundation, with active network of dedicated health care professionals, epidemiologists and patients. Most of our work is done for free. We could do so much more if we would be able to increase our financial support. Any form of support that could help built our financial structure to a more sustainable structure is very

welcome.
Endorsement of multidisciplinary and international collaboration are key to detect patient-treatment to outcome patterns to improve cancer care. Prospective auditing and registry is costly and some human resources to keep the network running is very much needed. Please, consider supporting us in more ways.

The best wishes for the holidays from the EURECCA team.

Cornelis