Launched of INSPIRE at EBCC 10
INTERNATIONAL NIPPLE SPARING MASTECTOMY REGISTRY

At the 10th European Breast Cancer Conference, (EBCC-10) Amsterdam, the Netherlands, the Principal Investigators, Professor Isabel Rubio, Spain, and Professor Riccardo Audisio, UK, proudly launched the INSPIRE project. Invitations to prospectively follow patients undergoing nipple sparing mastectomy (NSM) were sent last week to many centers of excellence, and the first signed investigator agreement has been received! There has been an increase in NSMs being performed for breast cancer/DCIS and risk reduction. However, there is a lack of robust evidence for the routine use of NSM. A prospective, consecutive and standardized registration pooling patients’ data together is required in order to overcome any selection bias or limited sample size. There is a need for this international registry because:

1. New surgical techniques need to be proven feasible, safe and validated before implementation. A well-designed prospective database is required to reduce uncertainty regarding NSM;
2. At present, a randomized clinical trial for nipple sparing techniques vs. conventional mastectomy is neither feasible nor ethical;
3. NSM is only performed by some breast units - therefore most patients and physicians are not fully informed about this alternative to a traditional mastectomy and reconstruction;
4. No standardized staging, surgical technique or surveillance protocol for NSM is presently available.

Looking forward to receiving your investigator’s agreement!
Dr Denise Hilling, MD PhD will collaborate with all centers in the IWWD project. The Bas Mulder award was raised through the cooperation of four research groups: Professor Beets-Tan and Professor Beets of the Antoni van Leeuwenhoek, Professor van de Velde of the Leiden University Medical Center and president of EURECCA, Alexander Vahrmeijer of the Image-guided surgery group, Professor Hospers of University of Groningen, and Professor Nagtegaal Radboud University Medical Center at Nijmegen.

We are very happy to report that the international watch and wait database for rectal cancer patients with clinical response to induction therapies, enrolled more than 650 patients within a year! This great success of participation of centers and actual patient accrual in the IWWD is the result of the dedicated network of the watchful waiting pioneers on the board of the executive committee. The executive committee consists of Angelita Habr-Gama, Gerarda Beets, Nuno Figueiredo, Rodrigo Perez and Cornelis van de Velde.

At this moment, the first 500 (retrospectively collected) patients in the IWWD are being analysed to describe the characteristics of the entered study population. Dr Denise Hilling, a talented trainee surgical oncologist, received the Bas Mulder Award of the Dutch Cancer Society/Alpen d’Huzes. This prestigious award will be used to further investigate the ‘Watch & Wait’ strategy by means of the prospective database and to study image-guided techniques optimising the identification of regrowths. To assure the prospective character of the database, patient data entered into the NEN-certified web-based database system ProMiSe of the LUMC should be updated with follow-up visits before the end of June 2016. For more information about the security of your patient data visit https://www.msbi.nl/promisec.

For more information on the IWWD, please visit the website www.iwwd.org.

The educational e-learning project, EURECCA, is currently in development. In March 2016, the proofs of the chapter ‘Cancer of the colon and the rectum’ were processed; this chapter, whose senior author is Harm Rutten, will form part of the textbook of the European Society of Surgical Oncology. The chapter will outline the classrooms and ‘state of the art’ web modules of the educational platform and will cover all aspects of colorectal cancer care. Learning objectives and questions and answers, which aim to optimize the learning effects of these modules, are in preparation.

EUROPACOLON is the driver behind this educational tool and once a version for clinicians has been developed, a platform for patients will be created. The ‘look and feel’ of the design for the educational platform is shown below.
Outcomes for patients with oesophago-gastric cancer are variable across Europe. The reasons for this variability are not clear. The aim of the EURECCA study was to describe and analyse clinical pathways to understand differences in service provision for oesophageal and gastric cancer in the countries participating in the EURECCA Upper GI group. A questionnaire was devised to assess clinical presentation, diagnosis, staging, treatment, pathology, follow-up and service frameworks across Europe for patients with oesophageal and gastric cancer. The questionnaire was issued to experts from 14 countries. The responses were analysed quantitatively and qualitatively and compared. The response rate was (10/14) 71.4%. The approach to diagnosis was similar. Most countries established a diagnosis within 3 weeks of presentation. However, there were different approaches to staging with variable use of endoscopic ultrasound reflecting availability. There has been centralisation of treatments in most countries for oesophageal surgery. The most consistent area was the approach to pathology. There were variations in access to specialist nurse and dietician support. Although most countries have multidisciplinary teams, the composition and frequency of meetings varied. The two main areas of significant difference were research and audit and overall service provision. Observations on service framework indicated that limited resources restricted many of the services. The principle approaches to diagnosis, treatment and pathology were similar. Factors affecting the quality of patient experience were variable. This may reflect availability of resources. Standard pathways of care may enhance both the quality of treatment and patient experience.

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EURECCA’s projects will be presented in various scientific symposia during the 36th congress of the European Society of Surgical Oncology, which will be held in Krakow. Our ESSO president Prof Audisio will welcome us on September 14th. On the same day, Prof Rubio will present on “Local therapy considerations in young patients: From breast conservation surgery to nipple sparing mastectomy” (Auditorium Hall 14:00). In addition, Isabel Rubio will chair and speak in a Meet the expert session on Nipple-sparing Mastectomy on the 16th. On September 15th, Dr Esther Bastiaannet, our senior epidemiologist, will discuss ‘Practical use of population based data’ in the management of older patients (9:00 Chamber Hall A). Also at 9:00 in the Theatre Hall, Prof van de Velde chairs a session on Quality Assurance in Surgical Oncology, hosting Prof Bill Allum, Prof Van den, Prof Rossi and Dr Wouters. Prof Beets is invited to speak on neoadjuvant treatment in rectal cancer in the Auditorium at 9:15.

Description and analysis of clinical pathways for oesophago-gastric adenocarcinoma, in 10 European countries
April is European Colorectal Cancer Awareness Month (ECCAM)

EURECCA was invited to join the EU Parliament Meeting in Brussels on March 2nd – hosted by Europacolon and the Member of the European Parliament (MEP), Dr Sant. The theme ‘Making Noise’ is intended to raise the level of discussion and awareness of CRC, which has the potential to be cured if identified early. Europacolon led by Jolanta Gore-Booth (Founder and CEO) and Geoffrey Henning (policy maker) represent the patients with colon and rectal cancer in Europe. Launched at the European Parliament in Brussels by EuropaColon in 2008, European Colorectal Cancer Awareness Month is an annual initiative held in March. Coordinated at European level by the organisation and by its Member Groups at national level. Predominantly organised by EuropaColon’s Member Groups, many events will take place throughout Europe during the month. The political momentum generated by ECCAM serves as an important advocacy tool and it has notably contributed to the advancement of National Cancer Plans and policies in a number of European countries in the past. In its ninth year #ECCAM16 aims to raise awareness of Colorectal Cancer across Europe and the Critical importance of screening.

European Colorectal Cancer Awareness Month
March 2016

#MakingNoise16 #GoBlue16 www.europacolon.com

Three people every minute around the world are diagnosed with Colorectal Cancer

EURECCA Breast update

The EURECCA Breast group was started in 2012, with the chair Riccardo Audisio. As a first initiative, EUSOMA and EURECCA collaborated in unravelling the adherence to quality indicators (QIs) of 27 EUSOMA certified breast units. In this dataset of over 40,000 patients, patterns of care were analysed. Mandy Kiderlen Eur J Cancer. 2015 Jul;51(10):1221-30. Adherence to QIs was the lowest compliance in the oldest patient group. An international comparison between Ireland and the Netherlands was published in PLoSOne (PLoS One. 2015 Feb 3;10(2):e0118074). In a dataset of approximately 47,000 patients treatment and survival were compared for patients above 65 years. The International comparison of Marloes Derks was introduced at the ECC 2015, Vienna. This International comparison (n=120,000) will appear soon, unfortunately Sweden withdrew at a late stage. Questionnaires are being prepared for distribution among ESSO members to study the variation among surgical oncologists with regards to the positive and negative axilla in breast cancer. Moreover, Riccardo Audisio has planned a GOSAFE project – safety for elderly breast cancer patients. For INSPIRE please see the FrontPage news.
EURECCA initiated an international survey to share and compare patient outcome for oesophagogastric cancer. This study assessed how a uniform dataset could be introduced for oesophagogastric cancer in Europe. Participating countries presented data using common data items describing patients’, disease, strategies, and outcome characteristics. Patients treated with curative surgery for squamous cell carcinoma (SCC) or adenocarcinoma (ACA) were included. United Kingdom, the Netherlands, France, Spain and Ireland participated.

There were differences in data source ranging from national registries to large collaborative groups. 4668 oesophagogastric cancer cases over a 12 month period were included. The predominant histological type was ACA. Disease stage tended to be earlier in France and Ireland. In oesophageal and junctional cancers, neoadjuvant chemoradiotherapy was preferred in the Netherlands and Ireland contrasting with chemotherapy in the UK and France. All countries used perioperative chemotherapy in gastric cancer but 1/3 of patients received this treatment. The mean R0 resection rate was 86% for oesophageal and junctional resections and 88% for gastric resections. Postoperative mortality varied from 1% to 7%.

This European survey showed that implementing a uniform treatment and outcome data format of oesophagogastric cancer is feasible. It identified differences in disease presentation, treatment approaches and outcome, which need to be investigated, especially by increasing the number of participating countries. Future comparisons will facilitate developments in treatment for the benefit of patient outcomes.’


Common variables in European pancreatic cancer registries: the introduction of the EURECCA pancreatic cancer project

‘Quality assurance of cancer care is of utmost importance to detect and avoid under and over treatment. Most cancer data are collected by different procedures in different countries, and are poorly comparable at an international level. EURECCA, acronym for European Registration of Cancer Care, is a platform aiming to harmonize cancer data collection and improve cancer care by feedback. After the prior launch of the projects on colorectal, breast and upper GI cancer, EURECCA’s newest project is collecting data on pancreatic cancer in several European countries. National cancer registries, as well as specific pancreatic cancer audits/registries, were invited to participate in EURECCA Pancreas. Participating countries were requested to share an overview of their collected data items. Of the received data sets, a shared items list (core data set) was made of items that are present in 7 out of 11 datasets. This common item list, creates insight in similarities between different national registries and will enable data comparison on a larger scale. Additionally, first data was requested from the participating countries.

Over 24 countries have been approached and up till now 11 confirmed participation: Austria, Belgium, Bulgaria, Denmark, Germany, The Netherlands, Slovenia, Spain, Sweden, Ukraine and United Kingdom. The number of collected data items varied between 16 and 285. This led to a shared items list of 25 variables divided into five categories: patient characteristics, preoperative diagnostics, treatment, staging and survival. Eight countries shared their first data. A list of 25 shared list of items on pancreatic cancer coming from eleven participating registries was created, providing a basis for future prospective data collection in pancreatic cancer treatment internationally.’

de Leede, Sibinga Mulder et al. Accepted EJSO 2016.
We are a non-profit foundation, with an active network of dedicated health care professionals, epidemiologists and patients. We are supported with a grant of ESSO and most of our work is done in kind. One of our weaknesses is that we could do so much more if we could increase our financial support. Any form of support that could help build our financial structure into a more sustainable one is very welcome. Endorsement of multidisciplinarity and international collaboration is key to detecting 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.

Support EURECCA

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EURECCA (acronym for EUropean REgistry of Cancer CAre or EUropEan CanCer Audit), started in 2007 as an ECCO/ESSO initiative. EURECCA is an international multidisciplinary platform of clinicians, patients and epidemiologists aiming to improve the quality of cancer care by data registration, feedback, forming plans for improvement and sharing knowledge of performance and science. EURECCA is registered as a foundation based in Leiden. Relevant background: Still considerable variation exists in Europe in cancer management and outcome. Moreover, there is an urgent need for transparent uniform international data collection and analysis, in order to monitor and learn from all aspects of cancer care and to provide feedback and education. Uniform datasets are necessary, and not existent yet. Collaboration is the key word in getting there.

Do enlarged lateral lymph nodes in rectal cancer after CRT lead to preventable lateral local recurrences?

Recent literature suggests that patients with enlarged lateral lymph nodes (>5mm on MRI), who had neoadjuvant chemoradiotherapy and standard TME, have an up to 80% local recurrence rate in the lateral compartment; half of which has no distant spread. Currently, a multi-center pooled analysis is ongoing to study the (lateral) local recurrence rate in patients with low locally advanced rectal cancer with enlarged and/or heterogeneous lateral lymph nodes on the pre-treatment MRI. Because of the low incidence of these specific patients, we need as many centers as possible to participate. Please contact us and join! More about this study soon on the ESSO website.

Miranda Kusters, surgeon