



## Masterclass 2018 Report

Jola Gore Booth opened the meeting to an audience of patient advocates, speakers, colleagues and guests. She addressed some of the issues and opportunities of EuropaColon. These included the **planned transition to a digestive cancer future**. Finally, Jola thanked everyone for their hard work and commitment to supporting patients over the past year.

The next speaker was EuropaColon's Medical Director Professor Eric Van Cutsem (Belgium) who opened the session on **Knowledge is Power** with a look at the **challenges of treating different stages of colorectal cancer (CRC)**. New opportunities have brought more treatment options and better understanding of how to use them as they are absorbed into the pathway. One of the new developments has been to modify the adjuvant therapy regimens to 3 months, for low risk patients. This has less long-term toxicity and is already being used widely.

He also talked about the **importance of molecular biology** in understanding the many treatment options available. Such analysis shows the differences of the cancer for each patient. Whilst a better understanding of RAS, HER2, BRAF, MSI is useful there are still large numbers of patients where more detailed information is not available. The increasing molecular aberrations in CRC are being followed up with new drug opportunities in development.

**Public perceptions around colonoscopy** were addressed in two presentations. Firstly, Dr Amlani presented results from a new public survey on colonoscopy. Of the 3,000 citizens surveyed, 59% reported their experience was better than anticipated and 35% that it was what they expected.

The embarrassment caused by the experience, however, seems to remain. Spanish people felt most negatively about their colonoscopy, followed by France and Italy. The good news was that 43% of people were less embarrassed after a colonoscopy than before. The survey also revealed that doctors were the most trusted source of information and the internet the lowest. Patient group websites were fourth.

Dr Hasan (Italy) talked about **bowel preparation for colonoscopy**, saying that 20 years ago it was complex and difficult for patients. He stressed that tolerability was an important factor for most patients. However good bowel preparation was key as without it, no actual prevention was taking place. In 1980, 4 litres of fluid were required to clean the bowel, this fell to 3 litres by 2000 but in 2010 a major advance took this down to 2 litres.

Professor Ole Thastrup (Denmark) spoke about the **importance of prognostic markers** to help identify the patients' sensitivity to medicines. His company has developed an assay that assesses 400 medicines and their ability to treat some 150 cancers. Every patient is different so it is important to develop tools to make sure that each patient receives the right treatment at the right time for the best outcomes. The treatment options are expensive and it is important that the life of a patient isn't wasted experimenting with different options.

The assay takes a sample from the tumour and as it grows and develops it is then assessed against every available medicine. A recommendation is made to the treating clinician as to which medicine has the best sensitivity and likely to give the best outcome for the individual patient. He is hopeful that in time we will develop a global standard for matching the individual cancer patient to an effective drug therapy.

Professor Domenico D'Ugo (Italy) spoke about **Surgery options for patients**. He opened his presentation by stressing that without a well co-ordinated and managed Multi-Disciplinary Team (MDT) the patient will not receive the best standard of care. The MDT is the key to quality care throughout the patient journey, adding that in France treatment is not reimbursed if the patient is not reviewed by the MDT. There is now considerable evidence that centres with a well functioning MDT have better patient experience and outcomes are more successful. In addition to an efficient MDT, the number of patients treated is also a pre-requisite for better outcomes across all disciplines.

Professor D'Ugo spent some time discussing the **Essential Requirements of Quality Cancer Care** these he felt were important markers for patients to consider when deciding on where to be treated.

The Enhanced Recovery After Surgery (ERAS) protocol has proven the value for patients. The benefits of carefully organised services with up front preparation and planning both pre and post-surgery are considerable. Dramatically reducing the time spent in hospital and the likelihood of quickly returning to normal daily routine.

Professor D'Ugo closed by encouraging patients to demand better care and to change their hospital if they felt that they would receive better treatment somewhere else.

Melissa Konopko (UK) presented the **Genome Project** and the work of the Sanger Institute. Despite this being a relatively new project they have moved steadily to increase the amount of genome data available. In 2012 only 1% of people had a full sequence, by 2017 this had reached 17% and it is expected that by 2022 upwards of 80% of people will have their genome sequence completed.

At present, it is mostly achieved in rare diseases and cancer, where it is currently assisting in clinical practice. In most cases genome programs are run and funded by national governments who have recognised the potential cost savings.

However, there are challenges: healthcare is not accustomed to this level of data and tools are needed to make best use of it. Furthermore, clinical data is often not comparable and in addition the data needs to be mobile so that people can use it where ever necessary. One key criterion is flexibility. The way it is being set up to allow the benefit to be multiplied through sharing and collaboration will determine its long-term success.

Stefan Gijssels (Belgium), EuropaColon's new Executive Director, is helping to manage the progress of the organisation's new strategy and the move into registration in Belgium. He presented the plans and vision for the renaming to "**Digestive Cancers Europe**".

This ambitious plan will create a new organisation that will cover all the digestive cancers in time. While the speed of the progress will depend on funding and resources, the plans encompass support for the existing groups as well as opening the organisation up to wider opportunities.

Zorana Maravic (Serbia) opened the second day with news about the **Unmet Needs of Patients Living with mCRC Survey**. Some results of the survey from the four countries that have finished with the recruitment (Hungary, Spain, Serbia and Poland) were presented and showed lack of awareness of colorectal cancer among the surveyed patient population. It also demonstrated that the screening programmes in those four countries need improvement, as only a small proportion of surveyed patients were diagnosed through screening programs. In general progress has been made towards the goal of recruiting 1,000 patients but there remain some countries where recruitment has been slow.

Plans for **European Colorectal Cancer Awareness Month (ECCAM) 2019** were presented jointly by Jola and Zorana. Zorana presented results and information about ECCAM 2018 showing dramatic increases in results generated during the month. This can be accredited to the greater involvement of all the EuropaColon groups.

Jola introduced a new project to be launched in March 2019. Based on the early results of the Unmet Needs of Patients with mCRC the Organisation plans a pan European Screening Awareness Campaign. The participants at the meeting were divided into groups and were invited to give their views on what the key messages of the campaign should be. These in turn will be given to the communications agency helping EuropaColon designing the campaign so that we can all agree a common message that will work in all countries.

Professor Stephen Halloran (UK) opened Day 2 of the meeting and reminded us of the considerable importance of, and future opportunities for the **intelligent use of FIT in screening** to detect early CRC. Sadly, the inequalities in screening he covered last year have advanced very little. Whilst new work has begun with five Member States (MS) supported by the EU Commission it has long way to go.

The presence of blood in stool remains a good marker. It is therefore important that Member States exploit the benefits of FIT in organised population-based screening programmes.

The referral rate to colonoscopy from a FIT-based screening program is limited by the endoscopy resource. The ability to adjust the FIT concentration threshold enable programs avoids unacceptable waiting times following a positive screen. Programs need to monitor screening endoscopy waiting times and adjust FIT thresholds in a timely fashion. They also have an obligation to campaign for more endoscopy resource when it is restricting the effectiveness of the screening programme!

Stephen explained that whilst FIT concentration alone is a CRC risk marker, at an individual screening episode, previous FIT results, their record of adherence to screening and their age and sex are also indicators of risk. CRC screening will begin to exploit all available markers of CRC risk by applying techniques like artificial intelligence and 'machine learning'. With these techniques we will improve the reliability of FIT screening and enable programmes to use the endoscopy resource in a more clinically and cost effective way!

We should all be aware of the risk factors for CRC and make a resolution to modify our life style accordingly. Stephen finished his presentation commending an intelligent and more personalised approach towards screening where a population-based program incorporates personal risk and personalises the interpretation of FIT data.

Louise Day (UK) looked at some of the **challenges with screening**. With compliance generally low with an average of only 1 in 7 citizens are taking up the offer of screening, a figure much lower than achieved for breast or cervical screening. Colorectal Cancer remains one of the most preventable form of cancer. Cervical testing are the most popular with people then breast and CRC is last. As she stated there are a number of historical and personal issues at play with CRC screening.

These issues are as much to do with reluctance to set up a system of screening as insufficient local resources. There seems to be more willingness to treat than preventing this particular cancer for some reason. While there is general agreement amongst many clinicians, policy discussions continually revolve around the age group to be screened, how this should happen, interpreting the results and regularity of screening. Even when a programme is up and running attitudes amongst the population lead to slow up take. Consequently on going awareness is essential if more lives to be saved through early diagnosis.

Ms Day urged the audience to keep their focus on the benefits of screening and early diagnosis and not be put off by rambling discussions and indecision in their country. Those able should continue to campaign for screening and awareness programmes so that more people can be diagnosed early.

This was followed by a **screening workshop**, looking at the good the bad and the ugly of the different regions with audience divided into regional grouping. The participants were tasked with sharing evidence and discussing progress of screening in their countries.

The range of responses was as might have been expected. CRC screening was not a priority for most governments and lack of resources in most countries meant that little awareness was being carried amongst the general public. The importance of public education was emphasised if governments were to maximise on the resources set aside for screening. While the groups present do their best, with limited funds this cannot reach as far as desired for greatest benefit.

**Biosimilars Debate:** One of the new opportunities for CRC medicines is the introduction of biosimilars to the market. These products were the subject of a debate with perspectives of the pharmacist, the clinician and the patient being presented and discussed.

Professor Steffen Thirstrup (Denmark) spoke first and immediately targeted the price differential between the originator and the similar product. He discussed the challenges to deliver a product with 'similarity' to the already approved product. One of these challenges being the difficulty to make and then prove similarity. He showed the process was akin to reverse engineering. The clinical requirements are considerable but at the same time less exacting than the original trials to validate an originator medicine. The demands placed on the manufacturer by the regulators are set very high and the new product is as highly regulated as the original. The first biosimilars appeared on the market in 2006.

He referred to a survey undertaken by the European Crohn's and Colitis Organisation. Noticeable differences of opinion were shown amongst clinicians and a considerable shift from their original position took place by the time of a second survey a few years later.

Dr Rosa Giuliani (Italy) a medical practitioner, stressed the importance for clinical perceptions to change with regards to these products as they become more widely approved. She noted that the conservatism that was prevalent in the early days of biosimilars has shifted and clinicians are now much more relaxed about using these medicines.

Dr Giuliani noted the benefit to patients with these new medicines as the lower prices mean that more people should be getting access to them. Indeed ESMO (European Society of Medical Oncology) has stated their desire for all patients to have equal access to medicines by 2020. By 2020 spend on medicine in the EU is likely to be around €1.3tr.

The patient perspective is important, they need to be told if they are receiving a biosimilar or the originator product. Patients should be comfortable that the science is understood, that the product has been suitably regulated and that there is collaboration between societies.

Stefan Gijssels (Belgium) presented the patient perspective and he stressed that no patient can know what is best for them all the time and needs guidance to make many decisions. He pointed out that biosimilars have been through a rigorous approval process and from his perspective are therefore trustworthy. Clearly they have a role to play in the future treatment of patients but accepts that an allowance could be made for variation between products.

Dr Carlos Hue (Spain) addressed the **importance of well-being**. His theory could be likened to the baking process, in that wellbeing depends on the ingredients. He opened his presentation by talking about work already undertaken in this regard by many leading authorities and talked through his understanding of this research and the results.

Happiness, he continued, was an active process, one that we all actively manage and input into. Also, it is important to add meaning to one's existence and here thinking plays an important part. The work of Maslow is important in determining the 5 stages of needs: The first level refers to the physical needs such as food, sleep, sex, shelter, and also, health. The second is connected with the need for security. The third refers to a feeling of belonging and being. The fourth is related to self-esteem and finally, the fifth refers to self-actualisation.

Health systems are overly focused on physical recovery and ignore the recovery that needs to take place 'within the patient'. He concluded showing how the different parts of the brain interact with each other and in so doing affect the state of mind and therefore the well-being of the patient. This area he feels is what we should spend more time working on.

Professor Nurdan Tozun (Turkey) spoke about the challenging topic of **younger people and CRC**. In her opinion 1:10 under 50 were now being diagnosed with the disease in Europe. The difference between this and a later diagnosis is that these are more aggressive, largely rectal cancers and more fatal than those of people diagnosed later in life.

Professor Tozun stressed the importance of constant surveillance if there was cancer amongst close members of the family, because of the hereditary nature of cancer in some cases. Wherever there is a 1<sup>st</sup> degree family member, regular follow up is essential even where there are different molecular profiles. For people suffering from inflammatory bowel disease for more than 8 years there is a case for surveillance every 2 years. A recent paper in

Gastroenterology showed 68% of young people diagnosed with CRC were diagnosed with Lynch syndrome and 24% with familial adenomas.

She concluded stressing that education was key for the future with an emphasis on healthy lifestyle, the importance of networking and guidelines with access to low cost screening to identify early symptoms.

Mike Isles (UK) has spent many of the past years working with ASOP on **fake and fraudulent medicines** and his alarming presentation showed how clever those working in the field have become. This expanding network of fake medicines makes money at the expense of the general population. The positive news is the Falsified Medicines Directive passed by the EU and adopted throughout Member States is having some positive outcomes already. However, even this is not sufficient and constant vigilance is needed.

This organised crime is a worldwide phenomenon with little concern for the health of those who purchase these medicines – usually online. He believes there are around 3,500 fake pharmacy websites and while people use them to save money, they don't realise the danger they are putting themselves in. Work is being done to stop this traffic but it is complex and challenging. There is now a common pharmacy licence logo that is needed for valid sites.

The third day of the Masterclass was introduced by Geoffrey Henning (UK) who discussed the new **Oesophageal/Gastric Cancer Patients survey** recently launched to help understand the experience and needs of this population.

Professor van Laarhoven (Netherlands) presented a very clear and comprehensive overview of the issues, **treatments and challenges** facing every patient with oesophageal or gastric cancer. This is one of the 4 deadliest cancers with respectively 20% and 30% survival rates. Currently there are resectable and non-resectable options available but neither are curable.

Data is showing that centralised treatment in large centres leads to better outcomes for the patient. This is the case not just for surgery where this is a well-known fact, but for other aspects of the pathway including palliative care. In the case of all patients it is not just about curative treatment but rather the involvement of all members of the Multi-Disciplinary Team (MDT).

Neo-adjuvant treatment (chemo and radiation) greatly increases survival but even here this only adds 4 years. Immuno-Oncology (PDL1) has the ability to disconnect the link to the cell and boost the immune system. However, this can lead to over active cells that in turn attack the body. Sadly 85% of patients have little or no benefit from current immune-oncology medicines. More research is needed.

HER2 medication offers 2 months additional life if the patient expresses this gene, but many clinicians still do not test for HER2. While there are a relatively large number of drug options, it has been shown that there is no real case to increase beyond 2 drugs because of toxicity.

From the patient perspective effective registry data can help understand the response far better as clear comparisons can be made between regimens and outcomes. Also gaining importance in understanding the patient experience is the increasing use of Patient Reported Outcomes in clinical trial and also daily practice. Early research is showing that patients have improved Quality of Life when PRO's are included.

Vitor Neves (Portugal) spoke about **EuropaColon Portugal** great success as a result of winning a prize in a recent international pancreatic cancer competition. Their hypothesis is that it is important to raise awareness of signs and symptoms of pancreatic cancer amongst the clinical population to enable early diagnosis. They conducted a survey of a majority of GPs in Portugal identifying the levels of knowledge in the 5 health districts in the country.

Armed with this information they will to undertake educational programs to increase awareness of pancreatic cancer amongst GPs. This they hope will increase the likelihood of earlier diagnosis and better outcomes for patients.

Ali Stunt (UK) spoke about the **awareness campaigns Pancreatic Cancer Action** had undertaken amongst the general public and GPs in targeted areas of the UK. The campaign was gradually increasing awareness and early diagnosis but the charity acknowledged this is a long process and work was constantly needed in campaigns of this type.

The most successful aspect of the campaign, which consisted of a number of different elements, was the diagnostic guide for clinicians. This resulted in specific messaging and hand-outs for clinicians and posters for surgeries. For the public a wide range of different options was embraced; posters in public toilets, social media, press advertising, bills boards outside targeted supermarkets, beer mats and a song.

Chris Curtis (UK) presented his personal experience of head and neck cancer and how this led him to start a new organisation called The Swallows in the UK, because it was difficult to swallow when you had this particular cancer.

His mission is to provide support to patients with this cancer. He has developed a very simple model that he is replicating across the UK, Australia, Spain and Portugal. The focus is a monthly meetings for the patient and the carer. Meeting in a hotel close to the central hospital the meetings start with everyone together but then split into patient and carer groups for the major part of the evening.

Between meetings he offers patients a 24/7 telephone helpline managed by volunteers. This he finds is essentially a tool for people to speak and off load their problems and concerns rather than seek advice. Advice is not encouraged. He also produces for each hospital a booklet that serves as a focal point. In the UK the model is already replicated in 25 centres and he expects to launch across Spain and Portugal by the end of the year.

Geoffrey Henning closed the digestive cancers session encouraging everyone to keep up the good work and help EuropaColon move into a new opportunity with Digestive Cancers Europe.