



An Interview with Jola Gore-Booth

Chief Executive Officer, EuropaColon



Jola Gore-Booth

Jola Gore-Booth founded EuropaColon, the first Pan European Not for Profit organisation dedicated to preventing deaths and improving the quality of life for those with colorectal cancer, in 2004. Jola's vision for EuropaColon has grown from long-standing experience and deep understanding of the needs and challenges faced by people with colorectal cancer. Previously, between 1997 and 2005, she was Chief Executive of Colon Cancer Concern (CCC), a leading UK colorectal cancer charity (now known as Bowel Cancer UK). Whilst there, Jola launched Bowel Cancer Awareness Month and the Bowel Cancer Forum – a collaboration of key stakeholders working together for the good of colorectal cancer patients and the general public. In addition, she has served on various advisory boards, steering committees, and achieved notable success with NICE on patient access to treatments. Jola saw the importance of collaboration and patient advocacy which drove her to create a colorectal cancer community by coordinating the development of patient advocacy groups across Europe. EuropaColon is an umbrella organization, represented by 43 groups across 32 European countries.

EuropaColon has four main goals; 1) to reduce the number of European citizens affected by colorectal cancer; 2) to identify colorectal cancer at an early stage; 3) to ensure access to the best treatment and care to all European patients; and, 4) to support novel and innovative colorectal cancer research. This interview focuses on the last two of these goals, which are most relevant to our readers.

Increasingly in healthcare we are seeing more involvement from patients, patient advocacy organizations, and disease foundations in the drug development process, as well as market access and reimbursement. Has EuropaColon been involved in activities related to drug development and/or market access?



This interview was conducted by Agnes Benedict, MA, MSc, Senior Research Scientist, Modeling and Simulation, Evidera.

The role of patients in drug development is an important topic and has been around for a long time, without much resolution. Should patients be involved in the development of clinical trials? I am often asked this question. Yes, of course, we think that patients should be involved in trial development, but it is a difficult challenge since manufacturers, clinicians, and patients often have different perspectives and goals that are not always easy

to reconcile. So the issue is at what point should patients get involved, and I don't have an answer for that. I feel that all stakeholders should, however, have this discussion sooner rather than later.

We are involved in guideline development. In 2012-2013, we participated in EURECCA's (European Registration of Cancer Care) first benchmark project on colon cancer. EURECCA's goal was to define core treatment strategies and develop a European audit structure in order to improve the quality of care for all patients with colon and rectal cancer through the analysis of data from national registries.

EuropaColon is also part of the new EU Joint Action on Comprehensive Cancer Control (CanCon), designed to facilitate the international cooperation and exchange of best practice between EU countries and to identify and define key elements to ensure optimal, comprehensive cancer care. We are providing the patient perspective.

We were also recently asked to provide input on a new Informed Consent document for patients entering into clinical trials. We referred this to our Expert Patient Advisory Group (EPAG), who reviewed the document and offered their opinions for consideration.

We are seeing a growing interest in patients and advocacy groups contributing to market access and reimbursement issues. Where does EuropaColon stand on that front?

In terms of market access, we are talking health technology assessment (HTA). Given that there is no pan-European HTA right now, it is at the national level where our groups can get involved. Bowel Cancer UK is a regular participant of National Institute for Health and Care Excellence (NICE) reviews. Barbara Moss, the Chair of our Expert Patient Advisory Group, has previously been involved with NICE appraisals and with the European Medical Agency (EMA), but that is the extent to our participation in that area.

You already mentioned your Expert Patient Advisory Group (EPAG). How many members serve on this group and how were those individuals selected?

We consider the EPAG an incredible strength of EuropaColon. There are currently nine members of this group who were recruited from our Associate and Affiliate Members. This is a very active group with true commitment and the members have already helped EuropaColon on a number of different topics.

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What kind of activities has this group participated in, and how can organizations contact this group if they would like to obtain their input on specific issues related to colorectal cancer?

Amongst others, they developed a patient leaflet on RAS (predictive biomarker) testing in colorectal cancer. They created a patients' diary enabling patients to highlight important questions to ask when visiting their oncologist or surgeon. The group is also involved in helping draft the program for our next Master Class. I can only anticipate the value of their contribution increasing even more with time.

Any approach to EPAG should come through the EuropaColon Head Office and we will discuss the project with the Chair, who is also a member of the Board of EuropaColon.

As a patient organization, your aim is bringing together key stakeholders in the fight against colorectal cancer. How does EuropaColon interface with key stakeholders (regulatory, pharma, clinicians)? Who do you work with exactly? Do you negotiate directly with national and European Union stakeholders, or do you leave it to your Member Groups to work at a national level?

That is an interesting question. Over the years, it has become accepted that EuropaColon is the voice of colorectal cancer patients at the European level. We have done various events in the EU Parliament, building relationships with Members of the European Parliament (MEPs), and working with our champions over the years. Politically it is hard work, but we aim to have a constant presence in Brussels and we do a lot of networking to support our goals. At a national level we support our Member Groups to develop and build their own relationships with their Health Ministry, MEP's, and Members of Parliament (MPs). Together we are making a difference.

We also work closely with many medical organizations. These include the European Cancer Organization (ECCO), the European Society for Medical Oncology (ESMO),

and the European Society of Digestive Oncology (ESDO) amongst others, and more recently with the European Society for Surgical Oncology (ESSO).

What is your relationship with biopharmaceutical and medical device and diagnostics companies? Do you feel you can have a role in working with industry to advance your cause?

We also sit on the European Federation of Pharmaceutical Industries and Associations (EFPIA) Think Tank made up of pharma and patient organizations to ensure patients have a voice in healthcare. This is a forum where very diverse issues of mutual interest are discussed and aired in a safe place.

We have long-standing working relationships with many in the pharma industry. As you can imagine, funding is always a challenge, so having support from industry companies is very important. We are transparent, however, and have clear contracts that outline what is expected of both parties when a company agrees to be a sponsor.

I would imagine that having good relationships with clinicians is also very important in moving your goals forward. How does EuropaColon engage with clinicians and what type of input do they offer to enhance your activities?

Honestly, the biggest challenge we have faced has been engaging with clinicians. First, clinicians are extremely busy and if you want to work with the best in the field it is a challenge to get their time. The younger ones, up and coming, are very focused on building their careers and concentrating on their practices and have less time to participate in outside activities. Many doctors also are less interested in the political part of healthcare; they want to focus on their patients and not necessarily get involved in advocacy. I can say, however, that progress is happening. Whereas the attitude used to be that patient advocacy groups were something clinicians had to “put

up with,” now there seems to be a better appreciation of what we are trying to accomplish. Over the years, advocacy groups have become more professional as well with well thought-out business plans, measurements of success, reporting of activities, etc., which brings another layer of respect to our community and makes us more credible at all levels.

How do you determine what research projects EuropaColon will get involved with, and how does that process work as far as stakeholders engaging your participation?

I would first like to say that this is a very early initiative for us, and to start, our focus will be on the small projects with truly innovative ideas. We are currently establishing a Scientific Committee that will be comprised of senior European clinicians. This committee will evaluate relevant requests for support and EuropaColon will help raise funds for those we feel hold promise.

We are also slowly expanding our remit into other digestive cancers as this is an area where patients are needing more support. Initially we will focus on pancreatic cancer and then gastric cancer.

In conclusion, what do you feel your biggest contribution has been in starting EuropaColon?

One of the biggest contributions and most rewarding has been the growth of our organisation across Europe. Together with our 43 groups we are making a difference in patients' lives through improved access to best treatments and care. At the same time, we are raising awareness of colorectal cancer - and the risks, signs, and symptoms of the disease - within the populations of Europe, and working towards achieving earlier diagnosis which will lead to more lives being saved. In the 12 years we have been established, our groups have developed into a very strong, committed, and vocal colorectal cancer community working together for the common good of all colorectal cancer patients and European citizens.