



EuropaColon

united against digestive cancers

EuropaColon

Annual Review 2016

EuropaColon Mission

“EuropaColon is committed to preventing deaths from colorectal cancer and improving the quality of life and support for those affected by the disease”

Established in 2004, EuropaColon is Europe’s leading umbrella colorectal cancer patient organisation acknowledged as the voice of the colorectal cancer patient community. The organisation’s 43 national advocacy groups aim to unite patients, carers, healthcare professionals, politicians, the media and the public in the fight against the disease. Through its Affiliate and Associate groups across Europe, EuropaColon is actively working to prioritise and raise the profile of colorectal cancer and to promote and encourage increased awareness of the symptoms and prevention of the disease. EuropaColon continues to campaign for the introduction of Formal Population Screening Programmes and conformity to EU Guidance and Policies throughout Europe

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Our 4 Key Goals

To reduce the number of European citizens affected by colorectal cancer

To diagnose colorectal cancer at an early stage

To ensure access to best treatment and care for all colorectal cancer patients in Europe

To support novel and innovative research into colorectal cancer



Mr Geoffrey Henning
Policy Director
EuropaColon
UNITED KINGDOM



Mr Keith Spencer
Director Special Projects
EuropaColon
UNITED KINGDOM



Mr Derek Vitali
Finance Director
EuropaColon
UNITED KINGDOM

Message from the CEO and the Medical Director

2016 will be remembered as the year that nearly brought EuropaColon to its knees! Funding promises made early in the year were delayed and agreed grants seemed to drift further and further away. Instead of moving ahead with our strategic plan, a large part of the year was devoted to chasing money and trying to stay afloat! It was thanks to the dedication, commitment and sacrifice from the EuropaColon team that we delivered as many projects as possible. It was therefore with great relief that we welcomed a new funding round at the end of the year – we knew then that EuropaColon would survive!

The most promising development of the year gave us the opportunity to engage afresh with the European Commission and open doors to some new initiatives that we hope will translate into better screening, care and treatments for patients with colorectal cancer. An invitation to meet Health Commissioner, Vytenis Andriukaitis, in April helped us stress how important it was to strengthen colorectal cancer screening across Europe. Fortunately the Commissioner endorsed our concerns and agreed to support us. Plans to roll out a programme to re-energise screening are currently being developed and will start in 2017.

After three years of discussions and raised hopes we finally managed to attract funds for a Survey of Unmet Needs of Patients with colorectal cancer. As this project depends predominantly on the endorsement and support of the clinical community we were most encouraged by the interest shown and the help offered. Recruiting patients for the survey is perceived to be our biggest obstacle and we anticipate that by asking clinicians to help us identify suitable patients we will reach our targets more efficiently.

We were invited to contribute to a new initiative from the European Cancer Organisation (ECCO) to participate in their project, Essential Requirements of Quality Cancer Care. Colorectal cancer and Bone and Soft Tissue Sarcomas were the first two disease areas chosen for analysis. The reports aim to supplement existing guidelines with recommendations for each area of the patient

pathway. 25 representatives from European Clinical Societies attended the two face to face meetings – these included medical oncologists, radiologists, surgeons, oncology institutes, nurses, pharmacists and psychologists. The patient voice was represented by EuropaColon and Sarcoma Patients Euronet (SPAEN). The reports will be published in January 2017. EuropaColon will be working with ECCO in the future to measure the adoption of these recommendations and will publish the results in our biennial Barometer.

We were delighted to welcome Barbara Moss and Zorana Maravic as new Directors of our Board and we look forward to a long and fruitful collaboration.

We also warmly welcomed Professor Stephen Halloran as our colorectal cancer screening expert and are most grateful for all the support and advice that he has given us to date. We look forward to working with him on new and exciting initiatives planned for next year.

I would like to extend my personal thanks to those who believed in EuropaColon during this difficult year, helping us to continue bringing value to colorectal cancer patients and the citizens of Europe.

Jolanta Gore-Booth

Professor Eric Van Cutsem

Professor Eric Van Cutsem
Medical Director
EuropaColon
Professor of Internal Medicine,
University of Leuven and
Head of Digestive Oncology
Department, University
Hospital Gasthuisberg, Leuven
BELGIUM



Mrs Jolanta Gore-Booth
Founder/CEO EuropaColon
UNITED KINGDOM

Expert Patient Advisory Group (EPAG)

The Expert Patient Advisory Group expanded its membership during 2016 welcoming John Ohene-Kodua from the UK. Most of the EPAG members attended the European Society of Medical Oncology (ESMO) meeting in Copenhagen in September and benefited from the lively discussion and exchange of opinions during the Patient Track. In addition, EuropaColon hosted a meeting inviting the Group to begin preparing a new patient education website to be delivered in 2017. This new website will offer, in addition to information about colorectal cancer diagnosis and treatment, useful hints and tips to support patients.

The Group commented and contributed to a number of projects during the year where their invaluable input was most welcome and gave useful insights.

European Colorectal Cancer Awareness Month – ECCAM

ECCAM in March, got off to a strong start with a meeting in the EU Parliament hosted by Dr Alfred Sant MEP (S&D). What none of the guests were expecting was for Dr Sant to refer to his own experience of colorectal cancer, fortunately diagnosed in its early stages. This moment was captured for us on film and then broadcast on TV in Malta where Dr Sant had a notable political career as leader of the Labour Party (1992-2008) and as Prime Minister (1996-1998).

Professor Stephen Halloran brought us up to date on implementing Formal Population Screening Programs and what that means. It came as a shock to learn that only seven countries in Europe were making progress on formal screening of their citizens. EuropaColon believes it is unacceptable that, eight years since the Council Recommendation of 2008 where the importance of Formal Population Screening was

stipulated; the situation in Europe is in a disorganised state. This new information led EuropaColon to conclude that efforts were urgently needed to re-energise screening across Europe.

Mr Anthony Rossi, a colorectal cancer survivor and member of the EPAG, spoke about his experience of colorectal cancer and how he was empowered to launch a new patient organisation in Malta. In addition Dr Luc Colemont spoke about the work of his Foundation, Stop Darmkanker and his challenges raising awareness of colorectal cancer in Belgium; Dr Luca Garulli had a most interesting presentation on minimally invasive surgery which he believes is the future of surgical interventions.

It was rewarding that as a result of the meeting in the Parliament we were offered an appointment to meet with the Health Commissioner.



Mrs Barbara Moss
Chair Expert Patient
Advisory Group (EPAG)
UNITED KINGDOM



Mrs Zorana Stokic
Director of Group and
Business Development
EuropaColon
SERBIA



Dora Constantinides
Pasykaf
EPAG Member
CYPRUS



Anthony Rossi
Malta Colorectal Cancer
Awareness Group
EPAG Member
MALTA



John Ohene-Kodua
EPAG Member
UNITED KINGDOM



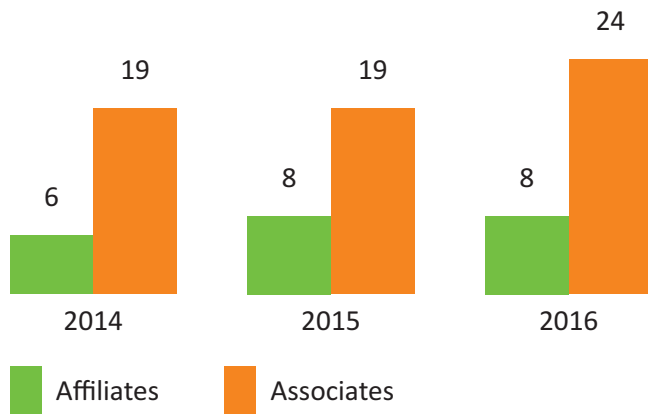
EuropaColon Networks Across Europe

EUROPACOLON NETWORKS

It is the intention of EuropaColon to have representation in every country in Europe to support patient with digestive cancers. But this is challenging despite constant efforts to connect with and work alongside other organisations in Europe. It remains our goal however, and with this in mind we have seen a steady increase year on year. We very much hope that all these organisations will attend the Masterclass in June 2017 to share experience and knowledge and help to grow their offering to patients.

An Affiliated Group has a direct affiliation with EuropaColon whilst an Associate Group is an existing cancer patient organisation working alongside us. Some groups are less active than others but our aim is to consistently strengthen our network to provide as much support as possible for colorectal cancer patients and their carers.

Growing Presence in Europe



AFFILIATES

EuropaColon – Germany

In March, in Dusseldorf, EuropaColon Germany together with Familienhilfe Darmkrebs organised a Patient Information Awareness Day attracting an audience of over 100 patients and carers. A formal launch of EuropaColon Germany took place in April in Berlin with a Press Conference and a good turn out followed by some positive media coverage. A first meeting of the Membership was held in December to share information and support.

EuropaColon – Portugal

In December 2016, the Ministry of Health started a Formal Colorectal Cancer Population Screening Programme with a regional roll out with immediate effect. For EuropaColon Portugal it was the culmination of a concerted campaign over many years. At the formal launch ceremony, the Secretary of State, acknowledged “This action is largely due to the way EuropaColon Portugal has pressed the Government to deliver it!”. EuropaColon Portugal was one of the first Groups to embrace pancreatic cancer as a step to supporting patients with digestive cancers. Throughout the year they carried out activities on social media and delivered 60,000 leaflets throughout the country promoting pancreatic cancer. In July they hosted a very successful conference on digestive cancers in Porto, open to the general public, health care professionals and patients.



EuropaColon – Latvia

2016 was intense with a strong focus on lobbying to improve the situation for colorectal and other cancer patients. This culminated in the collection of 10,000 signatures asking for an additional 10 million EUR spend for oncology. The “green corridor” (urgent referral) was established for newly diagnosed patients enabling all those suspected of having cancer to schedule an appointment with a doctor or specialist within 10 days. The Group also entered into new dialogue with the Health Ministry and Members of Parliament regarding the challenges in Latvia in oncology.

EuropaColon – Romania

Despite a challenging year, EuropaColon Romania managed to establish their new organisation, build a website, start a free stoma care support service with a dedicated colorectal cancer nurse and gather a team of gastroenterology-oncology-surgery specialists to provide counselling for patients.

EuropaColon – Slovenia

EuropaColon Slovenia continued to raise awareness and promote best practice amongst clinicians and the general public. They organised a number of public lectures alongside a larger symposium for health professionals that included family practitioners, gastroenterologists, gastro surgeons and nurses. The programme was prepared by Experts treating colorectal cancer patients and attended by an audience of 140 professionals from across Slovenia. The Group published two editions of their magazine, Koloskope, dealing with colorectal cancer and screening and included testimonials of colorectal cancer survivors.

EuropaColon – Spain

EuropaColon Spain initiated a new programme providing information on colorectal cancer in centres for senior citizens. The aim is to increase engagement in screening programs of the 'at risk' population (60+ years old). They organised six events with a total of nearly 300 participants. The Group participated in a National Cancer Patients' Congress with lectures given by a doctor and psychologist. The aim being to raise awareness of the work of EuropaColon Spain amongst the audience and to hopefully grow their membership. In a new departure they launched a series of three regional lectures on the psychological impact of cancer plus offering a roundtable discussion with four oncologists, attracting over 250 participants.

ASSOCIATES

Stop Darmkanker – Belgium

In keeping with the main focus of the organisation to raise awareness of colorectal cancer, during the year 132 keynote presentations were given to different

audiences. The Group continues with its considerable presence on social media, in addition to a popular awareness campaign organised in association with the Premier League soccer team, AA Ghent. The stadium was illuminated for four days with the Stop Darmkanker name and logo. The Inflatable Colon has featured strongly in raising awareness during the year. In addition, presentations were organised for a number of companies in Belgium to raise awareness of colorectal cancer emphasising the need to comply with the national screening programme. In addition, there were meetings with the Health Minister, three appearances on National TV and a successful collaboration with the Thomas More High School.



Pasykaf – Cyprus

Started in 1986 as a self help organisation Pasykaf continues its original mission to raise awareness, support patients and help those with a cancer diagnosis live with their disease. During a busy year Pasykaf made a number of presentations in schools, within communities and in organisations. Actions

during ECCAM were focused on complying with screening and displaying the Inflatable Colon to support the messages. Pasykaf is supporting digestive cancers and is a member of the World Pancreatic Cancer Day and World Pancreatic Cancer Coalition, raising awareness and supporting patients with pancreatic cancer. A growing element of Pasykaf is to provide direct nurse support for patients along with a new Rehabilitation Centre due to open in 2017.

Estonian Cancer Society – Estonia

After three years of intense lobbying and negotiating, the Health Ministry announced the pilot of a National Colorectal Cancer Screening Programme to start in July 2016. The age of screening will be adjusted every year, extending invitations until all citizens aged 60-69 are offered screening every two years. Citizens are invited to seek an appointment with their General Practitioner to obtain their test kit. In October the Estonian Cancer Society held a Press Conference to raise awareness amongst the general public of the screening programme. They updated their website on colorectal cancer to provide more information on prevention, symptoms and treatment options.

Association France Colon – France

As a result of considerable promotion and awareness raising the Group helped to increase screening compliance from 31% to 45% within the target age group of 50 – 74. A supporting factor was the switch to FIT (Faecal Immunochemical Test) which is considerably easier to use, coupled with a renewed commitment from family doctors to promote screening through their surgeries. A new initiative was the publication of a brochure for the next-of-kin of younger colorectal cancer patients. Previously young patients were left to inform their relatives with no

supporting information. France Colon expanded their activities in a number of French towns and cities.

Colores – Finland

Colores set up a closed web-based forum where colorectal cancer patients can communicate with one another. The Forum is available to all Colores members and allows peer support across distances. The site is monitored by doctors to avoid sharing of misinformation between users. The Group organised a two-day training programme for cancer patients helping them to adapt to a cancer diagnosis with presentations on related topics. The aim of the training is for those present to provide peer support for other patients. The plan is to expand this programme in the future.

Borka – Macedonia

During the year Borka organised a number of activities to raise awareness of colorectal cancer. These included a colorectal cancer conference with international speakers open to the general public. Publications included: a new information brochure on preventing colorectal cancer; they published in Macedonian and Albanian a new edition of their booklet “Living with metastatic colorectal cancer” in co-operation with the Ministry of Health and Public Health Institute of Macedonia. Volunteers continue to visit patients twice a week at the two main oncology centres to give them support and answer questions about their treatment. The telephone helpline remains a popular resource for cancer patients and families. A successful media campaign on the need for Formal Population Screening added to their work load.

Malta Colorectal Cancer Awareness Group – Malta

In February the Malta Colorectal Cancer Awareness Group was launched by the H.E. the President of Malta at the Attard Palace. This was followed by a presentation from the CEO with questions from the audience. In March, the Group held a seminar addressed by the President and the Minister of Health and the audience included doctors, nurses and members of the general public. During the course of the year they have been active working with the media with five TV and six radio appearances (a total of almost 500 minutes of air time) the aim being to raise awareness of colorectal cancer and screening.

National Screening Programme – Malta

In Malta, colorectal cancer screening is offered every two years. The programme started in 2013 – 2014 inviting people between 60-64, this was extended in 2015 to all citizens from 55-66. A strong focus has been on improving participation rates, which are already quite good but could be increased. The Screening Centre has improved quality assurance by adding extra surveillance.

POLA – Lithuania

In partnership with Transparency International and The European Healthcare Fraud and Corruption Network, POLA hosted a meeting in the Lithuanian Parliament on the many sided problems of corruption in healthcare. The meeting, attended by over 260 healthcare professionals, patients, patient advocates and policy makers, attracted extensive media coverage and a pledge by the newly appointed Lithuanian Health Minister to make tackling corruption a priority. The Group actively participated in the development of the National Cancer Plan as

well as in delivering other related activities. They are organising psychological support for cancer patients and relatives in health institutions as well as providing education on prevention and cancer screening.

Movement Against Cancer and Equal Right to Life – Russia

The Groups’ main event was the 9th Expert Forum “Movement Against Cancer” in February and is now one of the leading platforms to discuss public health, early diagnosis and treatment of cancer. The focus at this meeting was the need to develop a National Cancer Plan. All participants including leading experts in healthcare signed the appeal to the President and Minister of Health presenting solutions and measures aimed at reducing cancer mortality in the country. All the major diseases have a Strategic Plan but nothing has been set up for cancer. The toll-free hot-line processed around 2000 calls from cancer patients who receive support from medical specialists, this is also available via the website where people can get written answers on medical and legal issues that affect them.



Serbian Colorectal Cancer Patient Association – Serbia

During ECCAM the Association organised five events in major Serbian cities to raise awareness of Formal Population Screening, highlighting the importance of early diagnosis. The Inflatable Colon was a very popular feature at these events. These events led to increased co-operation and relations with clinical institutions and other bodies involved in the fight against cancer. Further support for patients and families was offered during the year in the form of lectures and panel discussions. The Association conducted a very successful patient survey on colorectal cancer with responses from 18 cities. The findings were extremely useful and will contribute greatly to the future work of the Association.

Dance with Cancer – Turkey

During the year Dance with Cancer continued their tour of the country with an Inflatable Colon for the third year and visited nine cities. As part of ECCAM they used the Antalya Half Marathon, to raise awareness of colorectal cancer and exhibit the colon. Over 30 runners participated to support Kanserle Dans (Dance with Cancer), runners included doctors, nurses, cancer patients and cancer survivors amongst many others.

Pembe Hanim – Turkey

The focus of Pembe Hanim is prevention of colorectal cancer along with the importance of good nutrition as a preventive measure. In order to raise awareness they organised several seminars in local municipalities as well as starting a new collaboration with a group called Young Dieticians. Activity during the year was limited by the political climate across the country.



Bowel Cancer – UK

Working with colorectal cancer organisations in Australia, Canada, France, and the US the new World Metastatic Colorectal Cancer Day was launched to highlight a need for real change in the treatment, quality of life and outcomes for patients with metastatic colorectal cancer along with the aim of reducing variations in access. Another focus for Bowel Cancer UK has been Lynch Syndrome which considerably increases the risk of colorectal cancer. A report published showed that 29% of hospitals were not following clinical guidelines that require an automatic test for all people under 50 years. It was followed by a second report exposing the way the disease is being managed. This work led to new draft guidance by the National Institute for Health and Care Excellence (NICE) which should lead to more people with the disease being diagnosed early. Ongoing lobbying led to the government introducing the more effective faecal immunochemical test (FIT) test for colorectal cancer screening. This test is already available in Scotland.

Strategic Plan 2016-2020

One of the most important in-house tasks of 2016 was to take a close look at the Organisation and plan the strategy until 2020. This gave EuropaColon the chance for a hard look at what it needs to do and how to do it. In addition to our commitment to grow and strengthen awareness and support for colorectal cancer patients together with our Associates and Affiliates across Europe it was recognised there were some important initiatives that needed to be addressed. One of these was how to re-energise colorectal cancer screening in Europe, with only eight countries approaching a comprehensive service a lot needs to be done. Perhaps most important is the survey of Unmet Needs of Patients with Metastatic Colorectal Cancer which for some time has been a high priority for EuropaColon. The results collected will be published and will hopefully assist Politicians, Ministries, Healthcare Professionals and Patient Organisations to better understand these unmet needs and help them to develop appropriate services to address them.



Please help us understand the Unmet Needs of Patients with CRC

Over the last two decades many clinical advances in treatment and care have taken place and with the introduction of screening more patients are surviving a diagnosis of colorectal cancer (CRC). However, during this time little work has been done to understand the Unmet Needs of Patients with the disease. EuropaColon, together with our Affiliate and Associate network in Europe, and other professional organisations, plan to conduct a survey for patients living with CRC and would like you to help us. The survey will help us to better understand what the need in terms of both clinical and non-clinical care is, what they consider to be a good quality of life, how we can improve our support services, and how we can have a strong representation of patients living with CRC in Europe and complex and

Prevention and Screening Booklet

First published in 2015, the Prevention and Screening booklet has been proven to be a great success. It provides information to people, who might be experiencing signs and symptoms of colorectal cancer or have friends or family who need advice. It seeks to address some of the taboos associated with colorectal cancer and urges people not to be silent. Sadly people do not tend to talk about this or indeed many other cancers! There is evidence that talking about cancer lets people know it's not something to be afraid of, also by creating less fear within the body enables the individual to face the disease head on and with courage.

Funding has been secured to translate the booklet into 21 languages. Copies will also be available on EuropaColon's website during the course of 2017.



Expanding the Remit of EuropaColon

Since the decision in 2015 to expand into other digestive cancers EuropaColon has been actively developing this new area of work. Two projects were quick to receive support, the World Pancreatic Cancer Coalition (WPCC) and the World Pancreatic Cancer Day (WPCD). They continue to grow in strength and appeal with each year bringing more new partners to join the platforms to raise awareness of this disease. In Europe, Pancreatic Cancer Europe (PCE) was established as a Not For Profit Organisation building on past efforts to increase awareness, expand research and develop political will to support this cancer.

The WPCC held their first International Meeting in Orlando, Florida with strong representation from all over the world, sharing information, exchanging ideas

and agreeing to collaborate in the interests of patients with this deadly disease.

EuropaColon was invited to join the Steering Committee of a new initiative – the Pancreatic Cancer Academy, under the auspices of the Central European Co-operative Oncology Group (CECOG). This two day meeting involved clinicians, researchers, nurses and patients/patient advocates sharing sessions and experience while gathering up to date knowledge about this disease. This was the first time such a meeting had taken place for pancreatic cancer where joint and individual sessions were additionally offered to the different groups of participants, leading to a useful cross fertilisation between all those present of ideas and thinking on research, treatment and care. The feedback from the meeting was extremely positive with a strong call for the format to be repeated.



Conferences and Meetings Attended:

Europe:

CANCON – The European Guide on Quality Improvement in Comprehensive Cancer Control; **ECCO** – The European Cancer Organisation; **EFPIA** – European Pharmaceutical Industry Association Health Collaboration Summit, Patient Think Tank; **EPF** – European Patient Forum; **ESMO** – European Society of Medical Oncology Congress; **ESO** – European School of Oncology – Observatory and Masterclass; **EURECCA** – European Registration of Cancer Care; **UEG** – United European Gastroenterology; **WCC/UICC** – World Cancer Congress; **WCGC** – World Congress on Gastrointestinal Cancers; **WPCC** – World Pancreatic Cancer Coalition;

Globally:

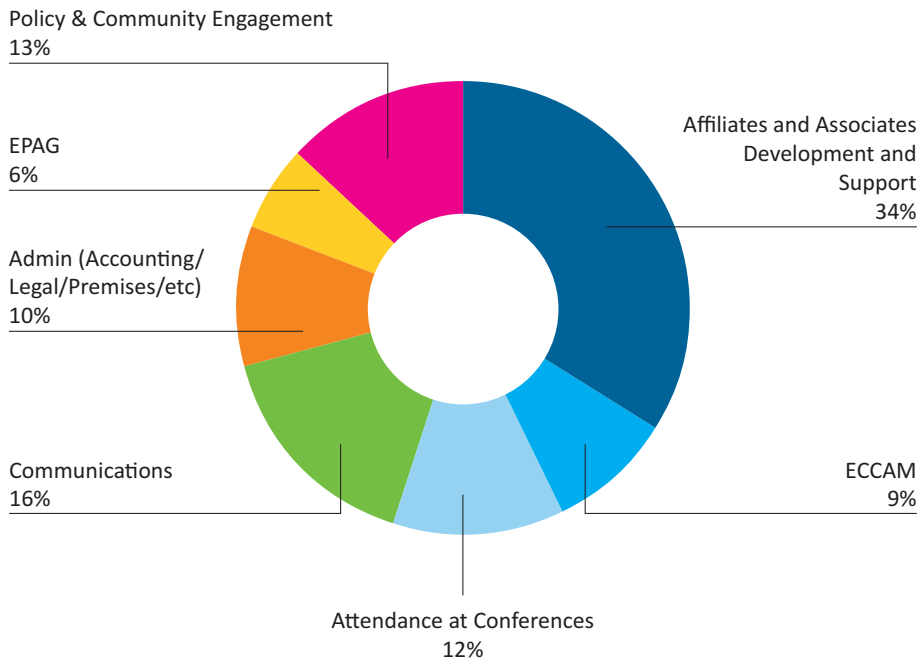
Brazil (**Global Colon Cancer Association** meeting in South America) Egypt (**Cancer From Patient Perspectives** – Cairo) and United States of America (**American Society of Clinical Oncology**).

Finances

EuropaColon is essentially a project driven Not for Profit Organisation. We receive funding for specific projects for a range of activities undertaken during the year. A small deduction from each grant covers our overheads, keeping us lean and dynamic but sometimes frustratingly so!

Our ideas for exciting new projects often exceed the funding available forcing us to trim some plans and abandon others. Sadly we often identify projects that will either support patients or advance the policy position but we cannot deliver these when funding is not available.

The graph gives an overview of the work delivered in 2016.



Sponsors

EuropaColon would like to thank all our sponsors for their generous support in 2016 and we look forward to working with them again in 2017.

Funding Partners



Collaborating Partners





EuropaColon

www.europacolon.com

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